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# "Continuing to work would keep my life normal"- A phenomenology of labor and work among mothers with cancer

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“CONTINUING TO WORK WOULD KEEP MY LIFE NORMAL” –  
A PHENOMENOLOGY OF LABOR AND WORK AMONG  
MOTHERS WITH CANCER

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A Thesis  
Presented to  
the Graduate School of  
Clemson University

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Arts  
Communication, Technology and Society

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by  
Kimberly Workman  
May 2016

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Accepted by:  
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## ABSTRACT

In 1989, years after many women had gained acceptance for working outside of the home, Hochschild (1989) coined the term “second shift labor” referring to the double burden of paid and unpaid labor experienced by working women. Hochschild’s work highlights social inequality and suggests that the perceived step towards equality that was commonly associated with women’s right to work actually had an adverse effect. It resulted in women, especially those with young children, working double shifts—the first one being their paid formal employment, and the second one being the housework at home. However, just as the women’s rights movement has changed in the past thirty years, so has our social world, and while studies show that there is still an unequal division of labor within the home (Brines 1994; Deutsch 1999; Garey 1999; Greenstein 2000; Gupta, 1999; Lennon & Rosenfield, 1994), little research has explored second shift labor in atypical circumstances, such as illness, that may reveal unexpected complexities to the concept.

Cancer is the second leading cause of death in the world and is caused by the overgrowth of abnormal cells in the human body (Sudhaker, 2009). Despite rapid advancements in technology, cancer is an extremely prevalent issue in America, and there are more than 100 different types (American Cancer Society, 2015). In total, it is estimated that 1,658,370 new cancer cases will be diagnosed in America in 2015. Among those newly diagnosed cases, 810,170 are expected to be women, and 277,280 women, previously or newly diagnosed with cancer, are expected to die as a result.

Preliminary findings from my research exploring the burden of second shift labor in the lives of mothers with cancer suggested that the women found opportunity within the burden of second shift labor to perform gendered identity work. Drawing on the theoretical perspectives of phenomenology and social construction, this thesis further explores these preliminary findings through the use of thirteen in-depth interviews. This expanded research suggests that unpaid work, or second shift, as well as paid labor and support, play key roles in the identity negotiation process that occurs when individuals are faced with a serious illness that causes them to redefine and adjust their normal life routines in order to accept or, in some ways, reject their “new normal.” While this does not justify or rationalize domestic labor inequality, it is important to understand the varying roles paid labor and unpaid work have in these mothers’ lives.

*Keywords:* Cancer, phenomenology, second shift, social construction, identity, motherhood, feminism, labor, technology, new normals, support

## DEDICATION

This thesis is dedicated to my mother, Kathy Treese, who has continually encouraged me, inspired me, and supported me throughout both my academic and self-journey. Her fearless determination to win her battle against cancer has left me awestruck and proud. I can only hope that I become half the mother and educator that she is.

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## CHAPTER ONE

### INTRODUCTION

On May 14, 2013, Angelina Jolie became the face of feminism when she published a piece in the *New York Times* discussing her decision to have a preventive double mastectomy because she carried the BRCA1 gene. The BRCA1 gene is a genetic mutation that substantially increases an individual's risk of developing breast and ovarian cancer. As a mother, Jolie claimed that a large part of her decision was influenced by the fact that she had children, because it would enable her to tell her children that "they don't need to fear they would lose me to breast cancer" (Jolie, 2014, p. 25). Jolie's decision was seen in the public sphere as a form of empowerment for women everywhere, because it encouraged women to be proactive about health; however, it also challenged the concept that a mastectomy can be associated with a loss of femininity. Jolie told the world, "I do not feel any less of a woman. I feel empowered that I made a strong choice that in no way diminishes my femininity" (Jolie, 2014, p. 25).

Jolie is an example of one of thousands of mothers who have experienced or are experiencing some form of cancer. While Jolie was fortunate enough to have the opportunity to choose preventive measures, some mothers are unaware of the risk of cancer until they have been diagnosed. Often those diagnosed with cancer do not completely stop their daily routines or cease to perform labor upon diagnosis but, rather, find ways for treatments and appointments to fit into their previously established schedules. The continuance of daily labor is particularly interesting in the lives of

mothers because of the unequal labor division that exists within the home between working men and women.

In 1989, sociologist Arlie Hochschild described the double burden of paid and unpaid labor experienced by working women as second shift labor. Hochschild's work highlights social inequality, and suggests that the perceived step towards equality, which was commonly associated with women's right to work, actually had an adverse effect. It resulted in women, especially those with young children, working double shifts—the first one being their paid formal employment, and the second one being the housework at home. Numerous studies have shown that, although men have responded to the unequal division of labor within the home by contributing more, women still perform the majority of work within the home (Batalova & Cohen, 2002; Brines, 1994; Diefenbach, 2002; Deutsch, 1999; Garey, 1999; Greenstein, 2000; Gupta, 1999; Habib, Nuwayhid, & Yeretian, 2006; Hook, 2006; Lennon & Rosenfield, 1994; Press & Townsley, 1998). However, even though studies show that an unequal labor division still exists, little research explores second shift labor in atypical circumstances, such as illness, which may reveal unexpected complexities to the concept.

My preliminary, exploratory research suggests that mothers with cancer found opportunity within the burden of second shift labor to perform identity work. In this thesis project, I expand those preliminary findings by drawing on the theoretical perspectives of phenomenology and social construction. In order to do this, I conducted in-depth interviews of self-identified cancer patients to ask, "What are the experiences of mothers with cancer?" More specifically, I ask, "What labor and work complexities are

involved within mothers' experience of cancer?" and "What technologies are part of their experiences?" Next, I perform a reflexive critical analysis of the interviews to identify common underlying themes of the experience of mothers with cancer. Given that my mother is currently fighting stage-four colon cancer, I decided to analyze the interviews in a way that did not bracket my experience but, instead, embraced it in order to offer a more complex understanding of the phenomena. Reflecting upon my experience afforded me additional insights into each transcript because I approached it as not only a researcher, but also as a daughter. Unlike other phenomenological studies of cancer (Arman et al., 2002; Bosisio et al., 2006; Fochtman, 2008; Park & Yi, 2009; Shaw et al., 2000; Velji & Fitch, 2001), this study does not focus on a particular type, stage, treatment, age group, or side effect of cancer but, rather, acknowledges that, although individual experiences are unique, the burden of labor experienced by mothers is similar. This general approach highlights common experiences among all mothers that transcend the borders of cancer types and specifications. In an effort to illuminate how mothers with cancer understand their illness through their experience of labor and work, this thesis is organized into several chapters. Chapter One introduces the thesis. Chapter Two examines the occurrence of cancer among women in America, reviews previous academic research on cancer, and explores studies regarding feminism and women's health. Chapter Three focuses on the laboring body and identity. Specifically, it examines the role of the body in the formation of identity, and the ways in which the body performs different types of labor. The fourth chapter justifies and explains the methodology and analysis. The fifth chapter describes the formal research design. Chapter Six presents

results, and the final chapter offers in an in-depth discussion of the results as well as the limitations.

## CHAPTER TWO

### BACKGROUND

#### **Cancer**

Cancer, a disease that causes the overgrowth of abnormal cells in the human body, has been plaguing mankind for centuries, with the first recorded case of breast cancer dating back to 1500 BC in ancient Egypt (Sudhaker, 2009). Currently, there are more than 100 different known types of cancer, and it is the second leading cause of death in the world (American Cancer Society, 2015). Despite increases in treatment, research, and awareness campaigns, such as “Think Pink,” cancer remains extremely prevalent in America. It was estimated that 1,658,370 new cancer cases would be diagnosed in America in 2015. Among those newly diagnosed cases, 810,170 were expected to be women. 277,280 women, previously or newly diagnosed with cancer, were expected to die as a result. According to the Centers for Disease Control and Prevention (2015), the three most common types of cancer among women are breast cancer, lung cancer, and colorectal cancer. Of those three types, lung cancer results in the most deaths each year. Research anticipates a continued increase in the global cancer burden due to the aging and growth of the population (American Cancer Society, 2015). It is estimated that by 2030, 21.7 million new cancer cases will exist, and 13 million cancer deaths will occur. No data exists on how many of the women living with cancer are mothers.

Despite feminist scholarship’s productivity in the fields of physical, emotional, and, mental health, much of the previous phenomenological research on women with

cancer has been conducted in medical fields (Dowling, 2007; Fotchman, 2008; Veiljii & Fitch, 2001), with little to no attention focused on the how the aspect of motherhood may change one's experience. While still valuable, studies conducted in medical fields often understand the body from a perspective of biological determinism, rather than social construction, or, more simply put, from a nature rather than a nurture perspective. Furthermore, much of the previous phenomenology research has focused on women with a particular type of cancer, such as breast cancer (Arman, et. al, 2002; Johnson, 1999; Nelson, 1996; Park & Yi, 2009). Qualitative health research on breast cancer suggests that it is both a negative and positive experience (Thomas-MacLean, 2004), and past communication research on cancer experiences in both men and women has been primarily focused on community building, information sharing, and empowerment through the use of computer-mediated support groups (Hoybye, Johansen, & Tjornjoj-Thomsen, 2005; Rodger & Shen, 2005; Sharf, 1997; Shaw et al., 2000; van-Uden-Krann et al., 2008).

By exploring these mothers' lived experiences of cancer post-diagnosis, this project contributes to a clearer understanding of the experience of paid labor and unpaid labor as well as the role of support during times of physical illness. While I acknowledge that different cancer types can result in different treatment experiences, and that each individual experience is unique and noteworthy, my focus on the aspect of motherhood, rather than cancer type, highlights commonalities among the stories of these women, which offers unique insights into the complex situation.

## **Cancerous Bodies**

While academic research on cancerous bodies exists, it is generally conducted in the form of questionnaires from a medical perspective, such as Schover's (1991) study on the effect of breast cancer on intimacy. She used questionnaires to ask breast cancer patients about their sex life post-diagnosis and -treatment. While this type of information is certainly valuable to medical personnel when considering treatment options, it fails to acknowledge the bodily, lived experiences of the patient. Research on cancerous bodies from a sociological perspective, rather than a medical one, is not widespread. Waskul and Van der Riet (2002) contributed to this gap in the literature with their research on the relationship between the body, self, and situated social interaction in terminal cancer patients. They claimed that cancer patients experience abject embodiment, meaning that they enter a "state in which coherent bodily boundaries erode and the self has little control over the leaking of blood, urine, feces, vomit, bile, pus, and various other hideous body fluids" (p. 487). The researchers conducted 72 interviews at a palliative care unit in a rural town in southern New South Wales, Australia, and found that patients were unable to ignore their diseased bodies. The abject body challenged the self's control over it, making it difficult to maintain a sense of dignity through the treatment process. They pointed out that a large part of this difficulty can be correlated to our understanding of what constitutes a normal relationship between the body, self, and society. Patients would not have struggled as much against the uncontrollable shut-down of the body, had it not been considered unnatural.

## **Feminism and Women's Health**

Feminist research in the field of women's health has been extremely productive, especially in the areas of reproductive, sexual, and, physical health. A feminist classic on research and women's health is the 1970 book *Women and Their Bodies*. This 75-cent, underground-published book was put together by a group of women who met and shared their personal experiences of health at a feminist workshop in Boston (Davis, 2007). Retitled *Our Bodies, Ourselves*, the book was revolutionary for its open discussion of sexuality and abortion. It contained a wealth of women's health information ranging from body image and reproductive health to politics and activism, and encouraged women to claim their sexuality. It spread quickly by word of mouth, selling 250,000 copies. In 1973, Simon & Schuster published the first commercial edition. The most recent update was published in 2011 by Judy Norsigian. The book has been translated into 29 different languages and distributed across the world (*Our Bodies Ourselves*, 2015) in an effort to strengthen and build a worldwide health movement.

Examinations of the discourses of health and body ideals are part of many studies that explore the ways in which the female body has been understood as a site of identity struggle (Benson, 1997; Davis, 2013; and Banet-Weiser & Portwood-Stacer, 2006) and product of cultural obedience (Wolf, 1990; Frith, Shaw & Shang, 2005). For example, Susan Orbach's 1979 research explores the ways in which body size and image are sites of struggle and empowerment for women. She claims that obesity is not a signpost of the moral failing of a female but rather an indication of deviance and liberation from cultural and societal pressures. According to Kirk and Colquhoun (1989), Western societies



associate health with a slim, well exercised, body. This discourse is reinforced through celebrity news and gossip that repeatedly show fitness as an avenue to thinness and an idealized body (Turner, 1999). This cultural association of fitness with thinness offers insight into the ways in which women's bodies are disciplined in an effort to obtain an idealized status. Tara Brabazon (2006) acknowledges this cultural understanding but also examines the way in which fitness can advocate feminism. She explores the relationship between women and sport by asking the question, "Why is it that the male sporting body is validated, while the female sporting body is medicated?" (p. 65). She combines narratives of her life with prior feminist scholarship to advocate for the ways in which fitness in women's lives can be viewed as more than a route to thinness but, rather, a way that encourages unfeminine behavior, because it increases the participation of women in a male dominated activities.

This insight and the rise of neoliberal culture, a culture in which every activity, even those that do not result in monetary gain or loss, is a market (Brown, 2015), informed feminist research into mental and emotional health. Scholars began examining the ways in which women engage in various forms of work in order to achieve an idealized body image that, in turn, affects self-esteem. Anita Harris (2004) describes modern society's effect on women from a neoliberal perspective as the creation of "the never good enough girl . . . must perpetually observe and remake herself finding herself and her behavior relentlessly pathologized in therapeutic language of self-esteem" (pp.34-35). One particular area in which we see this pathologizing discourse is the makeover TV show genre, which "promises to transform ordinary women into an

acceptable version of femininity through the relentless application of the transformative powers of surgery and dentistry, fashion advice, hairstyling, and expert make-up” (Tincknell, 2011, p. 84). These shows reinforce the idea that beauty is found in certain body types and fashion styles that result in feelings of insufficiency among women, causing them to engage in methods of recreating themselves in order to feel adequate.

## CHAPTER THREE

### LITERATURE REVIEW

Now that I have examined the prevalence of cancer in America and reviewed some of the scholarly research that takes place at the intersection of feminism and women's health, I will next explore the complex role of the body in everyday life. First, I will focus on the role of the body in identity, the use of technologies of the body in identity formation, and the effects of disease. Next, we will traverse the broad history of feminism, as both a political movement and an intellectual project, acknowledging ongoing debates about the usefulness of Foucauldian theory and thought within feminist scholarship. Finally, we will explore the ways in which the body labors and the unequal division of labor among men and women. Although this seems like a long journey through a widespread area of scholarship, it is a necessary one, as the narratives of the participants are complex and multi-faceted. As we explore the following areas of literature, consider one participant's, Diana's, narrative:

“The radiation was really really rough. What they do is they tattoo on the body. Little tiny pinpoints. Because they want to make sure you get the focus of the radiation exactly where it needs to be and not in other places so they did that and then I would go in once a week after school and have a radiation treatment. It was worse than the chemo for me. It was really really bad because my skin got so blistered and sunburned. I remember one morning I got up and went to the shower and all of the skin on my breast just fell off. I was just left there with nothing but

red meat. And I came out and I was crying...and my husband doesn't see me cry...unless it's sentimental he doesn't see me cry about pain or things like that. And for me to be crying he said what's going on and I told him and he said you're not going to school today and I hadn't missed any school up until that point and I said you're right I can't do school today. But I went anyways. I mean it hurt so intensely. But once it was over and it started to heal and for a while the skin was very dark and I thought oh okay I'm going to have two different colored boobs. And then the skin started getting lighter and lighter. It was cool. It was like having major sun tan."

### **Identity, Self, and the Body**

In Diana's passage, we can see the various ways in which the individual is struggling with and negotiating her identity. Although she is too ill to go to work, she still wants to go. Likewise, she worries about her "different colored boobs" but, overtime learns to accept them. Identity can be thought of as a social construction rather than a biological or spiritual essence (Clarke, 2008). Goffman's 1968 book *Stigma* explores the social construction of the self. He claims that the self is a dramatic performance an individual does in order to convince others of their identity within society. The self, for Goffman, is how an individual presents himself or herself to society. The attempt of an individual to ensure that their "self" identifies with groups, and does not deviate from societal norms, is the performance of identification. From Goffman's standpoint, the characteristics that individuals emphasize and deemphasize are denoted by the social situation. Goffman describes three types of identity: personal, ego, and social. Personal

identity is the aspect of an individual that makes them unique within society. This is the idea that each person can be defined by unique characteristics that separate them from others (fingerprints, DNA, etc.). Ego identity is our subjective sense of who we are and what we consider to be the “essence” of our identity. Social identity is comparative, in that it is the set of characteristics an individual seems to have when compared to others. Goffman says that, when we encounter an unknown individual, we assign them a virtual social identity based on our perceptions of them. *Stigma*—understood as a shortcoming—is then “based on the discrepancy between actual and virtual identity” (Clarke, 2008, p. 512). Goffman breaks stigma down into three areas: physical deformities and disabilities (missing limbs, handicap, deformed body), character blemishes (alcoholism, abusive history, class), and notions of race, nationality, and religion. In general, identity is not only determined in relation to other people and societal norms, but also founded through differences or dis-identifications.

Michel Foucault, another theorist of the self or, in his language, the subject, examines in *Madness and Civilization* how discourses of normality and sickness affect the knowledge of the “self.” Foucault analyzes discourses of sanity and madness in Western civilization and claims that normalization—the process of how ideas and actions are categorized as normal or abnormal—develops through discourses and institutions. He demonstrates how individuals who did not fit within a certain criteria of perceived “normalcy” within a society were institutionalized in asylums and, in turn, objectively “otherized.” The fear of being placed in an asylum not only influenced how individuals understood “the self” as a subject of knowledge about madness, but also was a tool of

government and institutional power. Governments not only had the power to create and maintain the knowledge of what is normal, but also had the power to reinforce it physically through the use of asylums, jails, hospitals, and other institutions.

**Technologies of the self.** In 1982, Foucault visited the University of Vermont to present at a faculty seminar called “Technologies of the Self,” in which he presented ideas on “how the self constituted itself as subject” (Martin et al., 1988, pp. 4). In other words, Foucault began exploring the ways in which individuals, by themselves and with the aid of others, attempted to transform their body or soul into what they perceived to be ideal. Foucault termed the actions that individuals undergo during this process as “technologies of the self.” He says technologies of the self “permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality” (Foucault, 1988, p. 18). The creation of the self through various technologies is not a new phenomena but can be traced all the way back to the early Greeks (Martin et al., 1988).

Throughout history, technologies of the self have served as a means to power within society. Foucault argues that the role of public opinion and the cultural understanding of normality have resulted in a loss of freedom of the self because they, in a way, establish a set of guidelines and principles an individual must adhere to in order to be accepted. This suggests a connection between technologies of power and technologies of self. If the process of normalization is developed through fear and accepted institutions, then individuals will engage in technologies that, at bare minimum, will

classify them as normal within society to avoid institutionalization, stigma, and other repercussions. For example, an individual born with a lazy eye may choose to have it surgically corrected in order to appear normal and avoid the stigma associated with a visible disability. Or in Diana's case, she worries about her "two different colored boobs" until she realizes that they look like a suntan as they begin to heal. Prior to their healing, the redness and "difference" in her appearance is concerning because it does not fit within the bounds of what society constitutes as "normal." However once they begin to heal and look like a suntan, Diana is able to cope with her appearance.

**Disease, culture, and the body.** By understanding technologies of self, we can begin to understand the ways in which the body functions as both a means of identity and power as well as a cultural symbol. Bryan Turner (2008) addresses the "tension between the body as a living organism and as a cultural product" (p. 1) in his book *The Body and Society*. He draws attention to the fact that current cultural understandings and medical technologies tint the ways in which a scientist sees and understands the body. Turner focuses on the process of embodiment and claims that, in order to truly understand the body, we have to study more than just its interactional context. In other words, "We have bodies, but we are also in a specific sense, bodies; our embodiment is a necessary requirement of our social identification" (1996, p. 42). In this quote, Turner is referring to the dualism between the body and the self. He is drawing attention to the fact that often times the body is ignored within sociological research, because it is understood as equivalent to the self, but, in reality, the body is the physical representation of the inner self. The intentional ways in which varying technologies of self are implemented on the

body carry meaning and offer insight into an individual's understanding of self. If we relate this back to the passage from Diana, we can begin to understand why the radiation treatment was so hard on her. Here we have a teacher that wants to work even though her current treatment regime makes it extremely difficult and painful to do so. The radiation was visibly affecting her body and therefore challenging her understanding of self. Diana was able to continue to be her "self" by continuing to teach. Perhaps taking a break from work while she was dealing with changes in her physical appearance would have been tough on her mentally. In other words, by allowing herself to appear normal on the outside she is, in some ways, showing others that she is also still normal on the inside.

Deborah Lupton expands on Turner's ideas and investigates the ways in medicine and healthcare are sociocultural constructions by exploring feelings and understandings associated with issues of health and illness. She argues that, "Western scientific medicine is just as much a product of social and cultural processes as are the medical knowledge and practices that have developed in nonwestern society" (2012, p. 8). To Lupton, medical culture goes beyond just medical knowledge and refers to the convergence of many meanings, such as cultural understandings of disease, illness, and treatment. Both the doctor and patient understand illness based on their own culture, society, religion, and knowledge.

### **Social Support**

Social support has been studied across multiple disciplines from both physical and emotional perspectives (Burlison, Albretch & Sarason, 1994). The five main types of support are emotional, esteem, network, informational, and tangible. According to



Albretch and Adelman (1987) social support is any form of “verbal and nonverbal communication between recipients and providers that reduces uncertainty about perception of personal control in one’s life experiences” (p. 19). Likewise, Cobb (1976) claims that social support takes the form of information and that information makes the individual believe he/she is cared for, he/she is esteemed and valued and/or he/she belongs to a network. In other words, social support offers individuals comfort in times of uncertainty. Originally, social support was found in physical spaces and physical interactions, however the widespread adoption of the Internet allowed for the creation of online support spaces as well, such as blogs, chatrooms, websites, etc. In fact, it has been argued that online spaces and social groups can be thought of as a new form of medicine (Owen, Boxley, Goldstein, Lee, Breen, and Rowland, 2010). Research exploring social support and cancer has been widespread. Cohen and Wills (1985) explored the relation between cancer morbidity and mortality and social support networks. They found that the size and function of networks directly related to survival and death rate of cancer patients. Beyond this, research has also explored the ways in which cancer affects relationships by removing the patient from routine habits (Bloom & Kessler, 1994; Bloom & Spiegel, 1984). The inability to continue to participate in routine social interactions may decrease the amount of social support to which the patient has access (Bloom & Kessler, 1994; Bloom & Spiegel, 1984). For the purposes of this study, it is important to understand the varying forms and roles of social support in order to fathom and appreciate the value it has in these participants’ lives.

## **Feminist Perspectives**

**Feminism as a political movement.** “Feminism” can refer to a school of theoretical thought or a political movement, both of which have transformed throughout history as women have gained more political and social rights. The feminist political movement can be divided into three distinct waves, all of which have raised questions about gender and power. First-wave feminism in the United States started in the late 19<sup>th</sup> century and is most commonly associated with the suffrage movement. Women of first-wave feminism addressed concerns about political equality and equal opportunity (Kroløkke & Sørensen, 2006). The political movements of first-wave feminism led to second-wave feminism, which developed in the post-war societies of the 1960s and 1970s. Second-wave feminist politics focused on, but were not limited to, attempting to pass the Equal Rights Amendment. It was critical of the female sexuality that was ideologically embedded within the industrial world, such as commercial definitions of beauty and womanhood. For example, the beauty industry was criticized for its narrow definition of beauty and feminine practices, which created an unhealthy body image in women’s minds (Bordo, 1995; Kilbourne, 1999). Sections of second-wave feminist movement fought for the desexualization of the female body and a multi-faceted concept of beauty that went beyond appearances dependent upon modern markets and beauty practices.

The 1980s gave rise to third-wave feminism and analyses of postfeminist culture. Aspects of third-wave feminism can be viewed as responses to the essentialist view of

womanhood seen in the first and second waves. A backlash to the word “feminist” associated it with many negative stereotypes (Lazar, 2009). Components of the third wave, such as “girlie feminism,” rejected the first- and second-wave critique of beauty norms and sexual objectification by embracing cosmetic practices and flaunting sexuality as a form of power. Concurrent with this, feminist media and culture scholars began to analyze the co-optation of such feminist ideals within what they described as a larger cultural climate of postfeminism.

Postfeminism is a term that originated in the United Kingdom and the United States to describe a cultural reaction against feminism (Lazar, 2009). Postfeminism is not a wave on its own but, rather, a feminist analysis of a new form of cultural backlash against feminism, this time praising and embracing some aspects of feminist politics, but while asserting that enough equality had been achieved to make the women’s movement no longer necessary. Postfeminist culture emphasized “a heightened female visibility in conjunction with notions of assumed freedom, agency, choice, pleasure, personal empowerment, and autonomy” (Lazar, 2009, p. 340). Unlike the political foci associated with other feminist movements, postfeminist culture was focused on the individual and her roles within society. For example, Imogen Tyler (2011) notes how the sexual politics of maternity transformed the pregnant mother image from abjection to idealization. She claims that the early 1990s represent a shift within pop culture because the visual image of the pregnant body was no longer confined to hospitals or households but, instead, plastered on billboards, television shows, and runways. Within this, she notes the rise of pregnancy photographers and maternity lingerie industries as exemplifying the mindset of

third-wave feminists. Instead of being critical of industries monetizing and defining beauty, women were now working and spending money to obtain the ideals set before them. The difference was that their role in the market was seen as a liberating choice rather than a societal pressure fueled out of a desire to be beautiful.

Lately there has been debate on whether we are still in a third-wave/postfeminist society or whether we are at the cusp of a fourth wave. According to Jennifer Baumgardner (2011), fourth-wave feminism has existed since 2008 and is marked by the role of online communication technologies that have led to online social movements and new feminist politics. The political thought behind fourth wave is understood as a “turn from concerns about ‘me’ to concern for the planet and all its beings” (Wrye, 2009, p. 187). The negative connotation associated with the word “feminist” in the 1990s is now beginning to take amore positive form, as celebrities such as Angelina Jolie, Miley Cyrus and Amy Poehler self-proclaim to be a feminists. Baumgardner notes that:

In place of zines and songs, young feminists created blogs, Twitter campaigns, and online media with names like *Racialicious* and *Feministing*, or wrote for *Jezebel* and *Salon’s Broadsheet*. They commented on the news, posted their most stylish plus-size fashion photos with info about where to shop, and tweeted that they, too, had had an abortion. (p. 251)

Whether or not we are in the midst of a fourth wave or still in the third, it is important to note the impact of online communication technologies that have been utilized by feminist activist groups to, not only spread their cause and increase the volume of their voice, but also to support one another through social networking and

forums by sharing and relating to common experiences and social battles. We see evidence of this in worldwide campaigns such as *The Everyday Sexism Project*, which recorded the lived experiences of sexism among women by collecting narratives through a blog and Twitter page. The campaign resulted in the rise of virtual activist communities, which allowed individuals to connect through experience, regardless of distance or location.

**Feminism as an intellectual project.** Feminism is not just a political movement, but also a theoretical, intellectual project. Feminist theory can be understood as a way to view the world that focuses on the inequality of women. Like any school of theoretical thought, feminist theory possesses its own epistemological understandings, assumptions, and debates.

***Biology is not destiny.*** In research prior to the 1960s, there is often no distinction between sex and gender when referring to the body, but, rather, the word gender is used to refer to masculine and feminine words (Nicholson, 1994). Some feminist scholars argue against the gender-as-nature assumptions (Eagly & Wood, 2013) by separating sex as the natural, biological influence and gender as the cultural influence (Unger, 1979). However, not all feminists agree that the distinction between biological difference and gender is important. For Judith Butler (1999), both gender and sex are merely social performances of the body because sex cannot exist outside of cultural and social meaning. She claims that our sexed bodies are discursively constructed, and the process of asserting an individual as either female or male is normative and, in turn, repressive. Modern feminist work on issues of gender and sex are extremely productive, exploring

ideas of gender essentialism (Witt, 2011) and concepts of what it means to be a woman (Haslanger, 2000).

**Foucault and feminism debate.** Despite the productiveness of Foucauldian theory across multiple disciplines, feminists hold varying opinions about whether or not his work belongs in feminist scholarship. McLauren (2012) argues that the debate on the productivity of Foucault in the world of modern scholarship is situated within a larger debate between the usefulness of postmodern thought. On one side of the debate, feminists argue that Foucault's rejection of the liberal subject impedes any possibility of progressive politics and female agency (Brodribb, 1992; Epstein, 1995). The other side of the debate argues that there *are* commonalities between Foucault and feminist theory, such as the body being viewed as a site of power and the emphasis of masculine privilege (Diamond et al., 1990). Although each side is grounded in different lines of feminist scholarship and influenced by different knowledge claims, to assert that the use of Foucault is correct or incorrect would be dismissive and unwarranted. For the purposes of this paper, Foucault's thoughts are utilized, because I believe that his understanding of the subject as a result of employed practices is particularly insightful when trying to comprehend the lived, embodied experiences of cancer and treatment.

**Foucauldian feminism.** According to McLauren (2012), Foucault's technologies of the self can be beneficial to feminist research. If scholars understand the Foucauldian subject as a product of employed technologies, we can see that the technological "practices both enable and constrain, and freedom is conceptualized as situated within material, institutional and disciplinary matters" (p. 3). According to feminist scholar Pini

(2004), the body serves as a physical site of the creation and destruction of self, and the technologies we employ upon it are “all the different ways in which we ‘work upon’ our bodies so as to become a self” (p. 164).

Rather than applying technologies of the self to bodies, Anne Balsamo (1996) critically examines the role of technologies of self in the creation and maintenance of gendered discourses about bodies and individuals. She explores “the ways in which gendered identities are technologically produced for material bodies” (p. 154) through contemporary beauty practices, such as exercising, and cosmetic and reproductive surgery, that are rooted in social circles, economic spheres, and government institutions. Balsamo claims that “utilization of technologies to achieve beauty and normalcy results in a process where ‘difference’ is made over into sameness” (p. 58).

Foucault’s thought has also been applied to feminist sports research examining how physical activity is itself a technology of the body (Cole, 1993, 1998; Duncan, 1994; Markula, 1995, 2000, 2001; Weseley, 2001). Markulu (2003) examines the ways in which female physical and athletic activity do not serve as a site of resistance but rather as a transgressive practice, which empowers women to challenge dominance by forcing them to acknowledge personal limitations (p. 104). Technologies of the self have also been applied to research on femininity in snowboarding culture (Thorpe, 2008) and the concept of female sexiness (Evans, Riley & Shankar, 2010).

**The female body as a site of struggle.** Feminist scholarship has long regarded the body as a site of power struggles, often examining the ways in which it further contributes to the subjugated state in which women live. Historically, women have been

limited because they are considered to be “more biological, more corporeal, and more natural than men” (Grosz, 1994, p. 4). Simone De Beauvoir (1949) examines the ways in which sex changes the way the body is treated throughout life, noting that females are often taught to avoid rough, dangerous activities, while males are encouraged to embrace them. Her phenomenological work on the lived experiences of the female and male body famously proposes that one is not born a gender but rather becomes a gender. Judith Butler elaborates on the idea that the body is not just a site of physical difference but also where gender is performed (1990). The visual appearance and differences of the body complicate this process, because they predispose women to the reproductive role due to the association of the female body with menstruation, pregnancy, and menopause. These differences have reinforced patriarchy because they have resulted in women’s confinement to the private sphere such as the home (Douglas, 1966; Lupton, 2012). As previously mentioned, women are constantly engaging in various forms of work in an effort to negotiate some sort of balance between power and embodiment.

### **Laboring Bodies**

**Labor versus work.** In order to accurately explore the role of labor and work in the lives of mothers living with cancer, we must first address the semantic differences. For the purposes of this research, concepts of work and labor can be understood from Karl Marx’s (1867) perspective. According to Marx, the performance of work results in a use-value, while the performance of labor results in an exchange value. Marx argues that, when an individual performs work, they are able to directly benefit and satisfy personal needs from the result of that work. However, when an individual performs labor, they are



alienated from the final result. Although the words are commonly used interchangeably in everyday interactions, this project understands labor as the *paid* labor an individual performs, because it results in an exchange value, and understands work as the *unpaid* work (emotional and physical) that an individual performs, which does not result in monetary gain.

**Women's oppression and labor.** According to Marx and Engels (1942) women's oppression is not an inherent, natural state but, rather, the result of many interrelated societal changes including the existence of private property, the development of the nuclear family, and the rise of capitalism. Marx and Engels argue that the rise of private property coincides with the loss of women's social power. They claim that, prior to the existence of private property, men may have performed more physically demanding labor (e.g., log splitting, farming, etc.) but women's labor was just as valued. After the rise private property, men were able to accumulate wealth, while women became viewed as a piece of that wealth. This new understanding of women as property gave way for the rise of the patriarchal nuclear family. Women's inferior position was furthered by capitalism's separation of household and commercial production. Commercial production was valued because it resulted in the accumulation of capital through monetary wealth, whereas household production was devalued and unnoticed. The lack of monetary compensation for household labor contributed to its invisibility, thus suggesting that women can only be liberated when unpaid household labor no longer exists.

Whereas such a perspective suggests that patriarchy is a secondary expression of class oppression, some Marxist feminists focus more directly on how factors and

conditions other than the woman's role in reproduction affect social power and reinforce oppression. For example, Sanday (1981) explores the ways in which creation lore among 150 tribes molded gender roles and social power. Likewise, Davis (1983) examines the ways in which race and class have consistently affected women's movements in the U.S.

**Industrialization and second shift.** Just as Marx and Engels (1942) note the relationship between women's oppression and the creation of private property, the development of the nuclear family, and the rise of capitalism, Ruth Cowan (1983) explores the relationship between the industrial revolution and the development of gendered labors. Cowan (1983) argues that housework is directly and ironically connected to industrialization, because the production of domestic technologies—such as the cast-iron stove and municipal water during the industrial revolution—freed men from their daily labor, but did not free women. Men were able to take on wage-paying jobs, while women continued to do housework and care for children. So, while technology was created with the hopes of reducing the amount of labor, it actually resulted in the opposite for women. Cowan claims that this was the start of women's predisposition to the domestic realm. Jeanne Boydston (1990) develops Cowan's ideas (1942) further by exploring the effect of wages on commercial production. She claims that essential unpaid work, such as housework, became increasingly visible with the increase of men performing commercial labor because of the lack of monetary compensation. According to Boydston (1990), unpaid work is less calculable, because there is no number or figure that enables its comparison to others. Therefore, the condition of the family property was attributed to the man's earning power, while the women's work to upkeep the property

went unrecognized. Although Marxist scholars argue that women must join the commercial working class to fight their oppression (Cliff, 1984), as noted previously, our contemporary societal condition exhibits ways in which working women are susceptible to a “double shift” (Hochschild & Machung, 1989) due to unpaid domestic labor.

**Gendered divisions of physical labor.** Gendered divisions of labor in feminist theory have traditionally focused on the uneven distribution of labor within the private sphere, especially after women gained acceptance in the work force. The term second shift originates from Hochschild and Machung’s 1989 work titled “The Second Shift: Working Parents and the Revolution at Home.” The term refers to the unpaid labor in the home experienced by many women, such as housework and childcare, which occurs after the career day has ended. In their work, Hochschild and Machung (1989) interviewed 50 couples and observed one dozen homes in order to investigate differences in leisure time, also known as the “leisure gap,” among men and women. They found that women had less leisure time than men, because they carried the burden of the second shift. They classified three different understandings of marital roles among the couples: traditional, transitional, and egalitarian. The traditional mother wished to identify with her roles at home as a wife, caretaker, and mother, while the egalitarian mother wanted to have equal power in the relationship and identify in the same social and political spheres as the man. The transitional was a mix of these two. In general, the working-class women understood marital roles from the traditional viewpoint, while the middle-class women understood marital roles from the egalitarian viewpoint. Hochschild and Machung’s (1989) research has proven to be extremely productive and has been applied to a variety of studies

concerning the unequal division of labor within the home (Brines 1994; Deutsch 1999; Garey 1999; Greenstein 2000; Gupta 1999; Lennon & Rosenfield, 1994; Press & Townsley, 1998).

Dworkin and Wachs (2004) conducted an analysis of the magazine *Shape Fit Pregnancy*, suggesting that women experience a unique third shift of labor post-pregnancy. According to Dworkin and Wachs, contemporary motherhood now requires a third shift of bodywork, because failing to do so represents “failed womanhood and motherhood” (p. 616). Other studies have also examined the pressure to remain fit during and after pregnancy from a perspective of neoliberal society (Jette, 2006; Nash, 2011).

**Emotional labor.** Hochschild (1983) does not just explore the physical labor that occurs in the public and private sphere, but the emotional labor as well. She defines emotional labor as “the management of feeling to create a publicly observable facial and bodily display” (p. 7). According to Hochschild, emotional labor that takes place within the public sphere has a monetary exchange value, and emotional labor that takes place in the private sphere, referred to as emotion management or work, has a use value.

Emotional labor is invisible work that an employee performs in order to project the appearance of what they consider to be appropriate emotions, such as enthusiasm, calmness, etc. Often, emotional labor is unacknowledged (Acker, 1989; Fletcher, 1995; Morris & Feldman, 1996). Hochschild illustrates her concept of emotional labor by exploring the ways in which flight attendants are trained to react during a crisis, and the way debt collectors are trained to exhibit sympathy for debtors. Feminist scholarship has drawn attention to the idea that, while both men and women perform emotional labor, the

majority of “emotion rich” jobs are filled by women (Colley, 2006; Fineman, 2005; Lewis and Simpson, 2007). However, despite its widespread application, many family studies fail to include emotional labor, as studied by Erikson (2005). Erikson conducted a quantitative study in which she surveyed families about labor within the home. Women reported that they performed more emotional work than men, and that they felt like there was a greater division of labor within the home than men did. She draws attention to the fact that emotional work is often mistakenly classified as love, and, therefore, often ignored within scholarship. Her quantitative data confirms the presence of emotional work within the home, but does not address the lived experience of it by women.

### **The Idealization of Motherhood**

Beyond the unequal division of labor within the home and emotional labor, ideas concerning the second shift and the idealization of motherhood were articulated by Susan Douglas and Meredith Michaels in their 2005 book *The Mommy Myth: The Idealization of Motherhood and How it has Undermined all Women*. In this book, Douglas and Michaels define what they call “new momism.” New momism “is a set of ideals, norms, and practices most frequently and powerfully represented in media that seem on the surface to celebrate motherhood, but which in reality promulgate standards of perfection which are beyond your reach” (Douglas & Michaels, 2005, p. 5). This unrealistic idealization of motherhood as the supermom is reinforced by the media constantly questioning the ways children are raised and wives act. The end result of new momism is unrealistic, with unreachable expectations that leave women feeling as though they have failed. Women’s attempts to live up to this idealization of motherhood could explain why

they are susceptible to second shifts within the household. Prior to this study, the concept of second shift work has still focused on physical labor, and has largely ignored the emotional labor that comes with motherhood. By understanding that the relationship between second shift work and the idealization of motherhood is a co-dependent one, we can further examine the different types of work in which mothers engage in an effort to live up to new momism. This thesis understands work not only through the physical actions which mothers go through in order to fulfill their role as an idealized mom, but also the emotional work a mother goes through during cancer, and how that work affects the ways in which they understand and take on their illness.

The understanding the social construction of identity through both technologies of the self and the discourses we reject and embrace through disidentification and identification, as well as understanding the differences between labor and work, allows here for a critical exploration and analysis of mothers' experiences with cancer. In order to appreciate and comprehend the labor and work these mothers engage in throughout their cancer experience, we must understand why labor and work exist in the first place, as well as the ways in which women are subjected to it. Drawing on these theoretical understandings, we can begin to understand the complex relationship between labor and identity as well as the role of technologies—mechanical and of the self—in the formation or maintaining of concepts of self when prior understandings are threatened by a serious illness—in this case, cancer.

## CHAPTER FOUR

### METHODOLOGY

#### **Research Orientation**

The decision to investigate the intersection of motherhood, labor, and cancer through a qualitative, phenomenological approach focusing on the lived realities of individuals was not an easy one. When considering the many options I had, I was constantly reminded of my own experiences and observations of mothers with cancer. Since the start of my high school career, I had watched two teachers and my own mother battle what was considered to be the same disease in very different ways. I began to notice that these differences could not be attributed to there being a right, or a better, way to fight the illness, but, rather, were because the lived reality of each of these women was very different. In other words, on a daily basis there were various facets of each individual's life, such as monetary concerns, and family and friend relationships, that affected their mental and physical state. This realization made me feel as though if I choose a methodology that did not give way to individual voices, I would be failing to acknowledge these differences and the fluid aspects of their individual lives. I felt as though the collection of lived experiences, gathered through each individual's account, led way to an enriching perspective, and understanding of this complex phenomenon, because it would empower these women through their own voices in a way that a statistical study cannot. As a result of the decision to focus on and value experience, I designed this qualitative research to be a phenomenological study from a social construction perspective.

## **Phenomenology**

The word “phenomenon” derives from the Greek word “phaenesthai,” meaning to flare up or to appear (Moustakas, 1994). The term phenomenology refers to both a theoretical understanding and a methodology. From a theoretical perspective, phenomenology was first used by the philosopher Kant in the 18<sup>th</sup> century (Moran, 2001), Husserl is often understood to be the father of phenomenology. Husserl (1970) contended that knowledge was developed through experience (Racher & Robinson, 2003). He argued that “lifeworld” is understood pre-reflectively (Husserl, 1970) and in a way that is free of cultural context. Crotty (1998) explains it as a way of understanding “experience before we have thought about it” (p. 95). In modern day social science, there are many perspectives within the umbrella of phenomenology, including positivist, interpretivist, and constructivist paradigms (Dowling, 2007).

Phenomenology as a research method emphasizes the common, lived experiences of a single group by exploring the narratives of the individuals within the group. Researchers in phenomenology “focus on describing what all participants have in common as they experience a phenomenon” (Creswell, 2013, p. 76), and work off of the philosophical assumptions that research is a study of lived realities, that participants are aware of their experiences, and that the research functions as a description of the experiences. (Creswell, 2013).

Since the origin of phenomenology as a methodology, several approaches to phenomenology have been developed, each with a different understanding of the role of



the researcher and depth of investigation. This study will draw on Gadamer's (1989) interpretive hermeneutic perspective that does not "bracket" researcher bias but, rather, embraces and acknowledges it. According to Travelbee (1971), human beings create meaning from the different experiences in their lives. This suggests that, no matter how simple and common an experience may seem on the surface, each experience an individual has is complex and embedded with meaning. An interpretive hermeneutic perspective of phenomenology enables us to begin to understand the embedded meanings. The Greek word "hermeneuein" translates to "interpret" or "understand" (Crotty 1998). Hermeneutic research dates back to the seventeenth century when it was used for interpreting scriptures in biblical studies (Crotty, 1998). It has since been used in a number of different ways (Giorgi, 1970, 1994; Giorgi, Fischer, & Murray, 1975; Moustakas, 1994; Smith, 1996) and in a wide variety of disciplines and studies, such as exploring the lived experiences of oppression (Bartky, 1990), of tourism (Cohen, 1979) and of the mind (Hegel, 2012), as well as investigating the complex relationship of pharmacology and biology in individuals diagnosed with schizophrenia (Kapur, 2003) and the experience of ecological development (Ulanowicz, 1986). Interpretive hermeneutics foregoes the idea that the world is measurable and, instead, investigates phenomena through lived experiences and encounters. According to Gadamer, conducting phenomenological research is a transactional process in which hermeneutics is a dialogue that employs constant interpretation by the researcher (Koch, 1999). This implies that findings are never concrete, but, rather, constantly interpretable and changeable resulting in a deeper, richer level of understanding.

This study utilizes the constructivist perspective of phenomenology that was first developed by Gadamer in his 1989 work *Truth and Method*. Unlike Husserl (1970), who contended that phenomenology should be examined free of cultural context, Gadamer (1989) argues that our prejudices and cultural knowledge enable a deeper level of understanding. According to Gadamer (1989), examining a phenomenon out of context inhibits the research process. In turn, he proposed a transactional approach in which hermeneutics is a dialogue that employs constant interpretation by the researcher (Koch, 1999). Within this perspective, “the hermeneutic process becomes a dialogical method whereby the horizon of the interpreter and the phenomenon being studied are combined together” (Dowling, 2007, p. 134.) As a daughter of a mother combating stage-four colon cancer, the use of Gadamer’s (1989) perspective was necessary in order to remain conscious and aware of my own perspectives in a way that inspires and mandates self-reflection.

### **Experience and Feminist Scholarship**

Experience has long been regarded as a source of knowledge in feminist scholarship. Susan Harding (1987) points out that there is not necessarily a unique feminist method, but, rather, it is the ways in which feminist researchers collect data that can be different. One of the primary ways in which feminist researchers have collected data and evidence is by conducting interviews focusing on lived realities and experiences. Johnson (1987) claims that

Feminist analysis, more than any other analysis of the human situation, has its origins in direct experience. All feminist theorists first observe and draw

conclusions from their own lives; all feminist theory results from the transformation of that experience and observation into principle. (p. 2)

Feminism's longstanding value for the authority of experience has not gone without debate, especially in the context of historical research. Butler and Scott (2015) acknowledge that, by writing an account of history through the experience of one class or a small selection of individuals, we are inadvertently failing to give a voice and acknowledge the experience, social position, and creation of others. In other words

Making visible the experience of a different group exposes the existence of repressive mechanisms, but not their inner workings or logics; we know that difference exists, but we don't understand it as constituted relationally. (p. 25)

Harding (1987) notes that the uses of female experience introduces new complexities, because "gender experiences vary across cultural categories" (p. 7) and are sometimes contradictory. Beyond these complexities, however, it is important to acknowledge and embrace—rather than attempt to 'bracket' or remove—that the sharing and collection of lived experience is interpreted on two levels. The words individuals choose to describe their experience are their own interpretative recollection, a process itself that is entrenched with meaning. Recognition of this can add another, rich layer to the analysis. Likewise, the words a researcher uses are a second level of interpretation. The researcher's understanding of the story is not a transparent mirror of the participant's interpreted memory, but a narrative construction of it. Feminist phenomenological scholarship faces the challenge of acknowledging the intersection between experience and interpretation as knowledge. Therefore, multi-level, interpretative understandings are

engaged and considered when writing and sharing research.

### **Data Collection: Active Interviewing**

Since experience cannot be directly accessed, interviewing can be used to access experiences as represented by the narratives constructed by interviewees. During an interview, a researcher is given access to previously private narratives, because it asks an individual about his/her personal experiences. Interview types can vary from structured to open ended conversations, depending on the type of informational exchange desired by the interviewer. Holstein and Gubrium (2003) argue that, even though interviews are mistakenly viewed as a source of bias or distortion due to the interviewer's involvement, the interviewer's active presence is vital in the research process. They note that meaning and information are not just created by the respondent, but that the interviewer has an active, unavoidable role in the conversation because of its interactional nature. Thus, the interviewer's role in the conversation makes the data collaborative (Alasuutari, 1995 & Holstein and Staples, 1992). Holstein and Gubrium (2003) propose that instead of trying to avoid the transactional process of an interview, interviewers should be "active," meaning that they should always be "consciously and conscientiously attending to the interview process and product in ways that are more sensitive to the social construction of knowledge" (p. 68). This can be achieved by discussing the "hows" and "whats" of the experience in order to understand the narrative at hand (Holstein and Gurbrium, 2003)

### **Data Analysis: Narrative and Normality from a Constant Comparative, Reflexive Approach**

The active interview process challenges the researcher to recognize narratives, or

stories, as more than simply a detailed conversation or an account of experiences. Instead, narratives can be perceived as performative acts through which we understand our existence in the human condition (Harter, 2012; Langellier, 2001; Maclean, 1988). Narratives are fluid as they are shaped and reshaped by corporeal, everyday experiences. In other words, “narrative imitates life, life imitates narrative” (Bruner, 1987, p. 13). Lynn Harter (2012) examines the role of narrative in health contexts in her book *Imagining New Normals: A Narrative for Health Communication*. Harter claims that individuals understand their lives through the compilation of small narratives into a metanarrative. Within these narratives individuals have the ability to choose the ways in which they represent themselves and others through the use of visual, audio, and verbal symbols (Harter, 2012; Burke, 1969). This ability to influence stories means that experiences are both corporeal, in the sense that they are felt in their raw form, and cultural, because they are embedded with meaning (McKerrow, 1998). That meaning is further strengthened through an individual’s recounting of their experiences, because they have the ability to choose the symbols through which the story is told and represented. This becomes especially problematic when asking individuals to describe a purely emotional experience, such as pain. Elaine Scarry (1985) discusses the difficulty in expressing physical pain and the adverse effects of pain on productivity, such as a blank mind or a loss of words, when pain is inflicted. In this instance, individuals do not have the words, or cannot comprehend the words, to explain their feelings. As listeners, the only way to understand that emotional experience is through the story of the individual, or narrator, describing it through words, gesture, body movement, sound, and images.

Here we find that the power of narratives is limited by the knowledge the narrator wishes to share, which can be further limited by recent experiences, current health conditions, memory, and mood. However, despite the limitations of narrative, it cannot be devalued because, it offers insight into an otherwise undocumented experience.

The routines and activities that fill our everyday lives can be understood as a self and socially constructed narrative of “normality.” Harter (2012) examines the ways in which chronic illness disrupts understandings of normal, because it changes previously established narratives. According to Harter, “when faced with novel, uncertain, and difficult situations, individuals can draw on narrative resources in their surround to (re)act and imagine new normal” (p.14). In order to move past a diagnosis of a chronic illness, individuals must find the creativity and strength to imagine a new normal. The imagining of a new normal allows individuals to understand their illness, such as cancer, as a small part of a larger narrative rather than as the essence of their life. This allows patients to “use narrative to craft a sense of who they are in light of bodily malfunctions and changes” (Harter, 2012, p. 17). The creation of new normals is essential to the patient’s mental health and attitude.

In this project, participants shared narratives of the struggle they had in maintaining their old normal during the cancer treatment process. Often these struggles were a direct result of physical limitations and redefined daily schedules due to treatment process. Many of the participants used the word “normal” when discussing previous routines and habits. The understanding of both old and new normals in the participants’

life allows for a clearer understanding to the ways in which work and labor are changed or remain the same.

### **Constant Comparison and Reflexivity**

Constant comparative method is a grounded theory approach to data analysis, or bottom-up approach, in which theories emerge from data analysis itself, first developed by Glaser and Strauss (1967). This approach calls for the comparison of new data with previously collected data in order to ensure that data will be “analyzed rather than potentially disregarded on thematic grounds” (O’Connor et al., 2008, p. 42). The process determines whether the analysis is deductive or inductive (O’Connor et al., 2008). The constant comparative method consists of four steps (Glaser, 1965). The data is first collected and coded based on a researcher’s original understanding of a phenomenon (Glaser & Strauss, 1967). After the initial data is collected there are three types of coding that can be performed: open coding, axial coding, and selective coding (Strauss and Corbin, 1990). This study utilizes open coding, meaning that the researchers go through “the process of breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss and Corbin, 1990 p. 61). The coding of the initial data then informs the collection of additional data. After the additional data is collected, the coding process repeats. This continues until the data reaches saturation.

In this study, constant comparative method was employed in three distinct ways. First, when performing the first read-through, I did not start with any previously defined categories, such as second shift labor, but, rather, I let the categories emerge in recognition of salient themes based on common subject areas. Secondly, after I realized

that work was once again a dominant theme, I dove into the theme more vigilantly, paying careful attention to how work related to the heart of the narrative. By doing this, and reflecting on preliminary research, I realized that, prior to this study, I had hastily grouped both paid labor and unpaid work into the same category. Interestingly enough, all of the participants of the study considered both paid labor and unpaid work to be “work,” and used the words interchangeably throughout narratives. However, despite their word choices, I classified each narrative based on its value as previously discussed. Narratives of *paid labor* were differentiated that narratives of *unpaid work* for the sake of research organization. Lastly, after the results were complete, but before diving into discussion, I took a moment to compare new categories with old data sets in order to reflect on previous or current possible misconceptions due to pre-established biases.



## CHAPTER FIVE

### RESEARCH DESIGN

#### **Exploratory Research**

In the spring of 2015, I conducted preliminary research exploring the lived experience of mothers with cancer through five, 45-minute, semi-structured interviews with personal contacts who had or were currently battling the disease. Data from this small sample suggested that the role of second shift labor during times of physical illness added previously overlooked complexities to the concept. In order to expand this preliminary research, I explored the lived experience of cancer, post-diagnosis by engaging with 13 semi-structured interviews of mothers who have experienced different types of cancer.

#### **Population and Sampling**

The type, stage of cancer, and treatment stage varied greatly among participants, as well as the age and current medical state (recently diagnosed, survivor, etc.). While I acknowledge that different types of cancer and levels of cancer involve different treatment methods, certain lived experiences of the disease remains similar in the sense that patients often experience the same types of treatments (chemotherapy, radiation, etc.). For this reason, I did not focus on any particular type of cancer. Rather, the study focused on the commonalities of both motherhood and cancer. Due to the sensitive nature of the disease, cancer patients are often a hard-to-reach crowd, so participants were chosen through previously established relationships and snowball sampling. I returned home to re-conduct interviews with the same five women from my preliminary research.

Then, through snowball sampling, I managed to find an additional seven participants. Snowball sampling afforded easier access to participants within the cancer community, because it allowed my participants to reach out to their friends about my work. In turn, I believe that this type of sampling, which developed through previously established relationships among participants, allowed them to feel like individuals rather than research subjects—which is crucial in phenomenological research. However, despite snowball sampling’s benefits for accessing hard-to-reach groups, it left no control for participant diversity, such as race, ethnicity, or socioeconomic class. The lack of diversity within my sample does not make it necessarily less valuable, but it should be noted. From an intersectional perspective, different groups may experience motherhood, labor, and cancer differently because of varying social situations and challenges. In other words, the lived experience of the Caucasian mothers in my first preliminary example can not be equated to the lived experience of African-American mothers or transgender mothers because of the varying privileges and challenges embedded within their lives. As argued by Butler and Scott (2015), it is important in future studies to research different groups in order to highlight suppression and exploitation in a way that contests rather than reproduces current ideological systems (p. 25).

### **Interviewing**

Of the 13 interviews collected, two were done via email due to each participant’s request and the remaining 11 interviews were done in person. One of the email interviewees said that she “preferred email because it allowed her to be more open and honest.” The interviews took place at the participant’s choice of location (coffee shop,

home, office, etc.). When considering where to conduct interviews, I decided that allowing the participants to choose was important, because it gave them the power to choose a location that they consider to be a safe place. I felt as though individuals were more willing to engage in conversations concerning hard to talk about subjects, such as cancer experience, more freely and openly in a setting of their own choice. The interviews ranged from 55 to 75 minutes long, consisted of five guiding questions regarding their experience with cancer and were audio recorded. Questions focused on exploring the experience of cancer as a whole and the experience of motherhood during cancer- (See Appendix A for a full list of interview questions). It was an active interview process (Holstein and Gurbrium, 2003), and follow-up questions were asked when more detail or clarification was needed in order to ensure an accurate description of the experience. Although in a few instances, when the subject appeared to be a sensitive topic, I chose to bypass follow up questions for the participant's well being. Occasionally when the overall interview seemed to be emotionally overwhelming for the participant, I chose to break up their narratives by intentionally changing the subject to conversations irrelevant to the study. I did this by asking questions about hobbies, recent news, children's activities, school systems, etc. Upon the conclusion of the interview, I collected contact information for each participant in case I needed to follow up with them at a later time.

### **Transcribing and Grouping**

Next, I transcribed the audio recordings into a Microsoft word document. I decided to break the interview into paragraphs based on subject changes, new questions,

and pauses over 6 seconds. Also, throughout the transcribing process I typed personal notes collected during the interview about data, mood, setting, and other interactional elements in italics, where appropriate. For example, in one interview I could see the struggle in a participant's face as she attempted to find the words to sum up her cancer experience. I could see the sweat form on her forehead as she repeated the word "tired" to me three times. I chose to write this down during the interview to ensure that during the analysis I remained conscious of the struggle one might have when asked to verbalize a feeling, such as pain. Furthermore, in effort to make the interview as comfortable as possible for participants, I took measures to ensure their anonymity. I performed all of the transcribing myself rather than risk their anonymity by hiring another company or individual, and I removed all participant names from the demographic data and changed the names of family members mentioned in the narratives. The voice recorder with the interviews was then locked in my advisor's office to ensure that no one else had access to it.

After the interviews were transcribed, an interpretive thematic phenomenological approach, similar to the method of Smith et al. (1999), was employed in which I engaged in reading and re-reading the participants' narratives, slowly clumping the data into units of meaning and consolidating those units of meaning into larger, more inclusive, and accurate thematic categories. To do this, I first printed out hard copies of the interview transcripts. While doing a first read-through, I hand-marked paragraphs by thematic subject area, such as physical work, emotional work, motherhood, treatment, support, technology, and so forth. I chose to do thematic subject areas, referring to the essence of

the paragraph, rather than the literal subject due to the unique nature of personal experiences and the varying ways in which those experiences can be described. I chose this method over in vivo coding, because I felt as though experiences were hard to vocalize due to the sensitive topics and feelings of pain that may be associated with the narratives. For example, organizing based on literal subject allowed me to partition narratives of unpaid work from narratives of paid labor despite the participants' word choice. Throughout this process, I found it difficult to have clear-cut categories, because similar subject areas were often spoken about in multiple ways. For example, some participants spoke of support groups as a source of motivation, while other participants spoke of support groups as a source of emotional and physical labor. If a paragraph touched on two subject areas, such as motherhood and emotional labor, both were noted in the first read through.

Next, I cut paper copies of the interviews up, paragraph by paragraph, and numbered them to ensure that I could reassemble the original order at any time, and then organized them into groups based on the thematic subject area that was noted during the first read through. After a second read through, I found that the vast majority of the participants' narratives fell into the categories of support, work/labor and negotiations of normals. Due to this, on the third read through, the data was examined and organized in categories through these three lenses. During this read through, I slowly clumped the data into larger units of meaning and thematic categories. I repeated this process until it felt like smaller groups of data could no longer be consolidated with larger groups due to thematic differences. However, it is important to note that these groups are not clearly

partitioned, contained categories but rather are interwoven and overlapping due to the complexities of each narrative. Some data was excluded from the analysis because it was irrelevant to the study. This data mainly included pure background information about their cancer, such as type, stage, age at diagnosis, etc., and narratives that resulted from intentional changes in subject in order to ease the emotional interview process. For example, the following was excluded because it was not relevant to the research:

Oh my god, the weather has been absolutely insane this winter. One day I feel like I have to wear every coat in my closet to go to work and the next day I'm like okay where are my summer dresses?

After all of the small groups that could be accurately consolidated were absorbed within larger groups, the remaining groups represented the meta-themes and subthemes that emerged from the process. Each category contained a set of quotes and examples from which the meaning emerged. Next, to ensure that I did not misunderstand or misrepresent an individual's narrative, I sent the categories with a brief description, and the quotes grouped underneath them, to the participants via email. All of the participants then had the opportunity to offer amendments or express objections to the quotes and themes.

## CHAPTER SIX

### RESULTS

As previously mentioned, after the second read through of the narratives, it was apparent that the three major emergent themes were work/labor, support and negotiation of normals. Work and labor were grouped together as one theme, due to the singular understanding in participants' lives but are referred to based on value. Work refers to unpaid labor performed because it has an use value, while labor refers to the paid labor that is performed because it has an exchange value. For this study, labor referred strictly to the participant's careers, while work referred to the emotional and physical tasks in other areas of their lives such as housework and attitude maintenance. Grouping them as one was imperative for organization, because often narratives spoke of both work and labor in the same passages.

Despite the popularity of research into online social support and information seeking by cancer patients, such technologies were largely absent from my participants' narratives. However, even though online technology was not a dominant theme, narratives of technologies of the self were present throughout the themes. For example, participants shared stories about their use of prosthetics and wigs in effort to transform their post-diagnosis appearance to more closely resemble their pre-diagnosed one.

The themes of work/labor and support were organized based on their relation to self and others. Next, each category was broken down into one additional organizational level for the purposes of presentation. The theme of negotiation of normals was organized based on whether the passage highlighted the ways in which the participant was

accepting the new normal or rejecting the new normal. Once again, it is important to understand that these themes should not be thought of as independent thematic groups or categories but, rather, should be understood from a relational perspective due to overlapping complexities. In other words, narratives classified under work/labor may also highlight avenues of support and illustrate the ways in which negotiations of normal are happening. To organize the research efficiently there is no way to create clear cut categories without compromising the complexity of these women's experiences.

### **Work/Labor**

Many of the participants' narratives about their cancer experience, directly or indirectly, focused on the idea of work. Work for the participants was understood as, not only the physical paid labor they performed outside of the home, but also the unpaid emotional and physical work they performed inside of the home, such as doing dishes, keeping a positive attitude, etc. For example, work was described by participants as "things around the house," "attend my son's baseball games," "make lesson plans," and "stay positive for everyone else." Consider the following passage from a participant's interview:

I never stopped. I was working, taking care of my house and my kids. Doing everyday normal things. Cooking, cleaning, everyday normal things. And I was able to do that until I had my surgery. I had a lumpectomy on my left side. And I'm left handed so for a few weeks right after, I couldn't do anything. But I more or less continued to do everything as soon as I could after I recovered. I don't know why. I guess I thought maybe me being normal would make everyone feel



better. It's like if you act like nothing is wrong then other people do to. And . . . honestly . . . I didn't have no help. My husband is not one to clean or cook anything. I mean he can't even boil water. He can cook breakfast, that's about it. So if I didn't do it, it didn't get done.

This passage highlights the broad understanding of the word “work” from participants. She describes the physical labor of, not only going to her job every day, but also the physical work around the house, such as cooking and cleaning. Beyond this, while she does not dwell on it, she mentions in passing the motivation behind her work was for others' benefit. Her claiming to do work and “act like nothing is wrong” suggests that perhaps she is subjected to the emotional labor of maintaining a typical or normal attitude, despite her true feelings, for others' benefit. Due to the participants' broad understanding of work, this theme was organized into work related to *self* and work related to *others*. Each of those categories was then sub-organized based on whether the participant's narrative was referring to physical work, emotional work, a combination of physical and emotional work, or changes in work as a result of cancer diagnosis.

**Work/labor related to self.** This section explores the various types of work performed during the treatment process for the patients' emotional well being and/or health. They are organized into either physical work, emotional work, or changes in work.

**Physical.** The work described in this section is the physical paid labor and unpaid work performed by participants during the treatment process in order to help their emotional or physical well being. For example, here one participant describes her

determination to get back to work in order to return to a “normal” life.

I didn’t wanna be sitting around thinking about being a patient all of the time so it was important for me to get back to work and get back to being as normal as possible, and that may have helped my children as well. I wanted my life normal, the way it always had been. In fact, after I had my radical mastectomy they told me minimal was six weeks out and after just two weeks I was like, “Well I’m just going to go back for a half day.” Especially because then I couldn’t exercise so I needed something normal again. So I did go back to work after two weeks but I did work short hours and built up into full days. I was all about getting back to normal.

In this passage, we can see how paid labor played a unique role in the participant’s life during the treatment process. Instead of the paid labor being a burden or a responsibility, the participant describes her participation in it as a link to or a piece of her normality and mental well being. Similarly, other participants described performing unpaid work around the house as, not only for their family’s benefit, but also for their own as well. One participant said, “I know it sounds silly but just being able to clean a little bit of the floor or do some of the laundry means a lot to me. It reminds me that I’m capable and that I haven’t given up.” Another participant said, “My everyday life was important to me during the treatment process. I felt like I had to keep doing everything I did at home normally. You know, for my sanity.” Participants also spoke about their decision to utilize the bodily technologies of prosthetics for their own well being. For example, one participant said,

“My cancer was 30 years ago but I never had the chance or the money to go through reconstruction. I had a lumpectomy on my left breast and well no one wants to walk around with a lopsided boob. It’s a confidence thing. I still wear a pad in my left bra to try to even out the size of the breast. But nothing works well.”

While initially this may not seem like physical work, we see here that the participant has taken time every day for the last thirty years to pad her bra in an attempt to make her breast sit evenly. She notes that she doesn’t do this for others, but instead it helps her own confidence. Likewise, another participant claimed that her wearing a wig helped her “keep her femininity” Although the majority of participants discussed physical work for self more than emotional work, a few touched on emotional work as well.

***Emotional.*** While testimonies about emotional labor were rarer than testimonies about physical labor, it is important to recognize that participants did not rely solely on physical paid labor and unpaid work for their own well being during the treatment process. The work described in this section is the emotional work performed by the patient for their well being. This includes using attitude as way to stay mentally well during the treatment process. For example, one participant said, “I have discovered that I use ‘denial’ to survive. I will ‘fake’ feeling good and just keep going until I actually do feel good.” In this short quote, we are able to see the ways in which the participant performs emotional work by forcing herself to appear as though she “feels good” for her own mental state.

Another participant reiterated this idea of positivity for their own health. They said, “I was always thinking that I had to stay positive no matter how I felt for the kids, but I know it helped me too. Being positive made sure that I never let ‘it,’ the ‘Big C’ beat me. The mind is a funny place.” Here we see that, while the participant used her children as a source of motivation for her positive mindset, her positivity did not only benefit her children, but herself as well.

***Changes in physical and emotional work/labor.*** Many participants expressed the ways in which their labor and work changed after diagnosis. This section illustrates the few moments when participants briefly changed their normal labor and work routines for their own health. For example, one participant said:

I tried to do as much as I could. But for about a month after the surgery they had to pick up some slack. Sometimes I felt guilty about it but sometimes I felt like ‘woo woo!!’ they finally had to do some of this. I kind of just decided that I would do what I could, and if it didn’t get done that day then it would get done the next. They did a lot for me that month, and it helped me a little with stress and recovery. Normally I wouldn’t let them do it, but that month I just needed to worry about me and getting back to normal.

This excerpt illustrates how, during the treatment process, the participant allowed her family to help with the housework for her own well being. By allowing her children and husband to “pick up some slack,” she was able to heal and focus on getting better without the added stress of typical day to day responsibilities. Another participant shared her feelings about not being able to perform paid labor. She stated, “It doesn’t bother me as

much right now staying home from work, because I know I couldn't make it a whole day at work because I get so tired, so fast." Both of these passages illustrate instances in which the participants made short-term changes in paid labor and unpaid work for their own health. Lastly, some participants spoke about the fear of cancer reoccurrence despite being liberated from the disease for an extended period of time. One participant said:

I never say that I'm cancer free because it's always there. I don't care how many years go by. I don't think I'll ever be able to say I'm cancer free. Even if they tell me that after 13 years, there is a good chance the cancer won't come back, to me it's always there. It's always in the back of my mind. Even when I get sick I always think okay maybe this problem I'm having is caused by the original cancer they can't find anywhere else.

This passage illustrates a new form of emotional labor that develops as a result of the cancer and exists in the patient's life long after they have been cured. Due to their previous cancer experience, they now have to mentally fight fears of cancer returning with every sickness or small ache.

**Work/labor related to others.** This section explores the various types of work performed during the treatment process by the patients for the emotional well being and/or health of others. It is organized into either physical work, emotional work, both physical and emotional work, or changes in work.

***Physical.*** The passages in this section include narratives of the physical labor and unpaid work performed by the patient during the treatment process for others' benefit. For example, one participant describes the physical work she performed during the

Christmas holidays for her family's benefit despite the fact that her children were grown.

She said:

I tried to keep everything as normal as possible. I was diagnosed right before the holidays and did not want it to put a damper on the season, so I tried to do everything we normally do at that time of year, such as bake cookies, make a big Christmas dinner, stuff Christmas stockings, so everything felt the same as usual. I felt like the closer I could keep things to normal would make it feel more like this was not going to be a major thing, just one more thing that we would have to deal with and work into our lives, not something that would change our lives.

This participant's children were 28, 26, and 23 years old and living on their own at the time of diagnosis, yet the mother still performed all of the usual holiday work such as baking cookies, making dinner, and stuffing stockings. In this example we see how the participant's decision to engage in the unpaid, physical holiday work was for her children's benefit rather than her own. Similarly, another participant shared:

My husband didn't do jack. I love my family. They're great, but in a way they're so used to mom having cancer it's like, Mom's got cancer, no big ass deal. I had to do everything that I always did. I did the cooking, the cleaning, the gardening, I went out and trimmed the bushes, I fed the pets. I did everything I always did, and again my husband is a good man, but he didn't do jack, and shit needed to be done. If I didn't do it then, it would've just been more work for me later.

This passage further illustrates the amount of unpaid physical work performed during the treatment process for other's benefits. Her husband and children did not help at all with her "second shift responsibilities", even after diagnosis and during treatment, with cancer.

***Emotional.*** This section illustrates the varying types of emotional work performed by participants during the treatment process for others' benefit and/or well being. For example in the following passage a participant recollects on the internal struggle she had with losing her hair. She shares:

I think the worst, like I said, was losing my hair. That was the worst thing for me. The doctor told me that I would definitely lose my hair, because I had what they called the red-devil. I had four treatments of that. He said my 14<sup>th</sup> day I was going to lose my hair. One day, I got up for work, I had long hair then, and I started fixing my hair and it just came out in globs. I just started crying. That was really the hard part. That's when I just said I'll have to get it cut. A friend of mine closed her shop and she cut it but she couldn't shave it all the way off. She said "I just can't do it" and I said well then cut it short enough that I can put the wig on. And she did. And I just let the rest fall out on it's own but that was hard too. You know seeing the hair every day falling out.

In this narrative, we see that, while her friend attempted to help her by cutting it short, her friend's inability to shave it created emotional work for the participant. The participant chose to sacrifice her own desire of being bald immediately after her hair was cut to ease the struggle of watching it fall out for her friend's feelings. While her friend was trying to help the treatment process by offering to cut her hair, her inability to shave

the participant's head resulted in more emotional work for the participant, because she still had to witness the hair loss. The participant claimed later in the interview that her hair was a symbol of her "womanhood." Seeing the hair loss daily required the participant to visually deal with the symbolic loss of her "womanhood," or, femininity.

Other participants spoke about the emotional labor associated with maintaining an omnipresent positive attitude for the benefit of others despite personal feelings. One participant claimed that she chose to be positive to avoid "making her family hurt." She said, "It's hard when you're going through something like cancer to deal with other people's emotions. I think that's why I went on and didn't allow it to bother me. Because if I allowed it to bother me, they would see it, and if they saw it, it would bother them." Another participant said, "I always stayed positive for my daughter despite how I felt."

These two participants illustrate a situation in which they performed emotional work by overriding their actual feelings for the wellbeing of their children and other family members. Other participants spoke about their use of technologies of self, such as a wig or prosthetics, for others' benefit rather than their own. For example, one participant said "I always wear something on my head, not because I feel like I need to for me, but because I don't want to make other people feel uncomfortable around me." Another participant who chose to wear a wig said, "I think that when people see me without hair they get uneasy like they might catch my cancer, and I don't want to ruin people's day." In both of these scenarios, we can see emotional and physical work. Emotionally, the act of putting on a wig, taking care of it, and purchasing it is a submission to others' need for normal that they must visibly watch themselves endure



every day when they look in the mirror to put it on and take it off. While at the same time, it takes physical work to not only put on, care for, and take off a wig but also to have the money to buy the wig for other's benefit. Each of the participants suggested that they would be okay with being bald but chose to utilize a wig to make other's feel more comfortable.

***Physical and emotional.*** While the previous excerpts have focused on examples of either physical or emotional work performed by participants for others, this section looks at narratives in which both physical and emotional work are performed. In other words, the work and labor described in this section is the physical paid labor and unpaid work as well as the emotional work performed by participants during the treatment process in order to help others emotionally or physically. For example, here one participant describes her using the communication technology of a blog about her health in order to lessen the amount of work for her husband and her son. A "caring bridge" blog is a blog for people going through an illness or disease. Its purpose is to allow the participant/patient to provide updated blogs instead of constantly having to answer the phone, etc. The participant stated

Because of the church I started a caring bridge blog. More so for my husband, because bless his heart, anytime we went to church fifty people were asking him how I was, and it was like he was saying the same thing over and over again. At first I was very resistant to the blog, because for me it was like a private thing. And it was like this is me and I'm going through all of this stuff, and I don't want everybody in the congregation to know what's going on with me. I realized that if

I could put this kind of information out there it would make it easier on my husband, and also easier on my poor son. I mean, he went to the school I went to and people would ask him “how’s your mom, how’s your mom, how’s your mom”, and so I found that once I started the caring bridge site it helped them. I also discovered that it was very therapeutic. I was careful about what I was putting in there because I’m a pastor’s wife and an educator, but it was good for me to put down what I could. Lots of people stopped asking my husband how I was all of the time and instead might say like “Oh I read she was having a rough day and we’re thinking about her”, and that made it easier for him. He didn’t have to constantly repeat himself or talk for hours about it.

In this passage, we can see how the participant began performing a new type of labor during her illness for her husband and son’s benefit. She began posting regularly to a caring bridge blog. According to the participant, the caring bridge blog is a place where you can update your current feelings and health status. The blog is only accessible by people who have the link to it. Interestingly enough, while health blogs and other similar technologies are created and marketed in a way that is meant to make it easier for the person diagnosed with the long term illness, this is an example of when the blog actually had, in some ways, the reverse effect. In this case, the patient then felt as though she had a responsibility to update the blog in order to make dealing with her illness easier for her son and husband. Her performing the extra physical work of regularly typing her feelings in the blog, and the emotional work of navigating those feelings, lessened the work of answering questions from friends and families for her son and husband. Similarly,

another participant spoke about how she chose to “always remain positive and do everything a mom would always do” for her son’s emotional well-being.

***Changes in physical and emotional work/labor.*** The passages in this section speak about the changes of work/labor in relation to others during the cancer treatment process, some of which lasted long after the cancer treatment resulting in a permanent redistribution of labor. These changes are changes that either increased or decreased work for the participant while having the opposite effect on others. For example, one participant said:

Since the cancer I have a different outlook on life. I don’t have to do it all. My house is not always clean. My husband and I share the housework more equally.

I still feel I do more, but he does a lot. Not because I ask him to. I think I just allow him to do more. Before, I wanted to do it all, because I felt it was my job as the wife and mother. Now I realize I can let a lot of that go. I still like things neat and tidy, but if things get messy, it’s okay. We spend more time having fun and just being with each other. I feel that the cancer was a good thing for my family.

We all know what is most important in life . . . each other.

This excerpt illustrates how the patient’s physical work around the house has actually lessened in two ways. On one hand, her husband’s physical work around the house has increased, and on the other hand she’s not nearly as concerned with the work, suggesting that she may perform it less often. Another participant said that during her cancer treatment her husband “took over buying groceries completely and helped with the vacuuming, since that was the hardest thing to do after surgery. And to be honest, he still

does those things today.” Like the other narrative, this passage illustrates the ways in which the participant’s unpaid work has decreased due to redistribution. Her husband began performing more unpaid work during the treatment process and has continued to do it even though the participant is considered to be “cancer free.”

### **Support**

Aside from work/labor, the other dominant theme was support. The numerous narratives of support were concerned with illustrating different avenues and outlets of support during the cancer treatment process. Interestingly enough, this not only included the ways in which individuals received support from others, but also the ways in which individuals supported themselves. This theme, although separated from labor, should not be thought of as exclusive to labor. It highlights an atypical understanding of support. Generally, when discussing support during a serious illness, it is viewed with little regard to the emotional and physical labor an individual must perform in order to engage in or accept that support. Furthermore, many of the participants highlighted the ways in which the support, both physical and emotional, from others enabled them or motivated them to continue to perform paid labor and unpaid emotional and physical work. For example, consider this passage from a participant:

My students helped give me a reason to fight. I found out in an activity planned by another teacher about a special challenge that each one of them had and had to live with, and there was no way I could let myself feel sorry for myself after seeing how strong they were.

We see in this passage that the type of support the students are offering is emotional in

the sense that it is motivational. The students sharing their individual challenges with the participant motivated her to maintain a positive outlook, despite the emotional work it took to do so. In this sense, the support helped the participant's attitude but also, indirectly, motivated her to perform more emotional work. Similarly, in some of the earlier passages concerning the physical or emotional work performed, you can see instances when the work actually resulted in some form of self support for the patient. For example, the participant that started the caring bridge blog said, in passing, "It was good for me to put down what I could." This suggested that the work she performed for others offered her some sort of support. The same can be seen in the passages addressing work related to self. Many of the participants talk about the ways in which normal routines helped them. For example, the bodily technology of a wig, for one participant, helped her maintain her femininity and confidence, once again exemplifying the link between labor and support in the participants' lives. In the following sections, the theme of support was organized based on the source of this support—friends, family, groups, etc.

**Support from others.** All of the participants repeatedly spoke about the ways in which they were supported during the treatment process. Some of the participants stressed the importance of "finding a support system" while others claimed that there was "never a time when they didn't feel supported. The theme of support highlights the ways in which emotional, financial and/or physical support was accessed throughout the treatment process. For example, one participant said:

My oncologist told me that there would be a certain day, like day 17 or 18 after my first treatment, when my hair would start falling out. I had told my good friend at church who is a hair stylist that I didn't want to deal with it being patchy and falling out. So as soon as it started to fall out I called her and just said I'm ready and she said "okay I'll come over" and when she came over we sat in the garage and we had a couple of beers and I said "just shave it" and she said "are you sure?" and I said yeah, just shave it all off. And she shaved it all off for me and scooped it up and put it in the trashcan really quick before I could see it. I did have wigs. This is an incredible part of my story. The people that I work with at my school. I was like the fifth teacher in a three or four year period diagnosed with cancer on our faculty and then we had some other cancer survivors and I didn't know this at the time but the fifth grade teachers that I teach with—I mean they were there with me right from the beginning—and they were like well at some point before you start your treatments, while you're still feeling good we're going to take you over to the wig shop and go wig shopping with you. And one of the girls had had leukemia like two years before so she knew exactly what I was going to need. And they're hilarious. We made an evening out of it. Of course the wig lady was super nice and picking out stuff that looked like the hair I naturally had. But of course the ladies kept bringing out like the long blonde hooker wig or the red hair and all these weird things. And I could hear them like they were trying on wigs in the main part of the shop. It was awful but fun and beautiful. They would like take pictures from the back for me so that I could see what it

would look like and they were just hilarious. They're fantastic. So I'm trying this on and then she's like well you need to get a wig and then you're going to want these little caps and just everything. Scarves and that kind of thing. Well I didn't realize how expensive it was. Because I was kind of stressing out. Wigs aren't cheap and all of the scarves and things aren't cheap either. And I was thinking how are we going to pay for this. I mean I know that all of these bills are coming and stuff. Then I notice that one of them is holding up her phone and their like well we have something to tell you. They had taken up a collection and they had two \$500 gift cards from the faculty and they said you can buy as many wigs as you want as many hats, scarves, whatever you want. And I just started crying. Well they were recording it and sending it out to everybody at school so that they could all be a part of it without having you know, 70 of us crammed into this little wig shop. And I had only been on staff there for two years. I hadn't been there that long but it was just amazing. They were like here and they handed them to me and I was just in shock. I was in shock.

This excerpt exemplifies a way in which a participant received both emotional and financial support from others, in this case, her friends and coworkers. Her friends supported her emotionally by helping her shave her head and quickly picking up the pieces before she saw them and afterwards turning a potentially depressing wig trip into a fun girls' outing. This prevented the patient from having to face the hard, emotional moment of hair loss alone.

Furthermore, her friends and coworkers supported her financially by helping her

pay for the wigs she needed from a collection taken up by friends and coworkers. Their support made this moment meaningful and memorable, despite the difficult time that hair loss is during a cancer patient's treatment. However, it is also important to recognize the overlapping relationship between support and work that is highlighted in this passage. In this case, the participant's social support comes from relationships built and accessed through her work environment. Without her job, her access to this type of social support could potentially be limited. Furthermore, she says one of her first thoughts was "how are we going to pay for this?" This concern about money and expenses throughout the treatment process highlights the tensions between work and support because the participant has to have the monetary funds to purchase the wig and take part in this form of social support. Support from others was organized into five sections based on the source of the support— support from students, support from employers, support from other patients, support from friends and family, and support groups and events.

***Students.*** Due to snowball sampling, all participants worked in education in some manner. Several mentioned the various ways in which students supported them during the cancer treatment process. One participant shared:

On my return from work after the initial diagnosis, a student that I never taught, I only knew her first name from talking to her while I was on duty, brought me a hand made card signed by over 100 students, most of whom I knew but had never had in my classroom. I also received emails from parents and former students telling me what a difference I had made in their lives, offering help and telling me that they were pulling for or praying for a full recovery. Even though I am not a



particularly religious individual, knowing that many people, some of whom I had only spoken to a few times, were all on my side lifted my spirits and encouraged me to do everything I could to win this battle.

The simple act of the students taking the initiative to show the teacher that she was an important part of each of their lives encouraged the teacher to continue fighting the cancer. Another teacher claimed that her students were great because they “were always on their best behavior during that time which made it easier to keep working every day.” Although these students supported the teacher in a different way, ultimately it had the same outcome. As previously seen the decision to work during the treatment process was a crucial part to the participant’s mental well-being. Her students’ good behavior supported her decision to continue working and, thus, indirectly supported her mental well-being.

***Employers.*** Some participants mentioned the ways in which their employers supported them throughout their illness by accommodating workload or work time in a way that allowed the participant to continuing working. For example, one participant said:

I found that I could no longer keep the hours that I did before the treatments. I no longer got up and worked at 4:30 am. Instead, I would go back to sleep after my husband left for work, or if I couldn’t sleep would lie in bed and read a book or sit in the recliner and sew. Although it was important to me to continue to work, work was no longer the focus in my life. I kept the same work hours, but all grading, and most preparation work, was done during my planning time or after

school before going home. Home time was dedicated to spending time with family or just relaxing and enjoying myself. Our assistant principal adjusted my schedule the next year, so that I was down to 4 subjects to cut down my preparation time and during the first full school year of treatment, cut me down to four classes per day. While this was nice, I felt bad about doing less than everyone else at work and asked to go back to five the following year. However, she continued to work with my schedule so that I could have all of my planning time in the afternoon, when I was more likely to be fatigued. This also allowed me to go to my treatments in the afternoons and only miss one class. The administration has continued to work with me, adjusting my schedule so I miss as little time as possible and allowing me to schedule doctor's appointments during my planning hour so I do not have to take off work.

This participant's employer not only willingly adapted to the patient's treatment schedule but also lowered the patient's normal workload in order to make her time teaching less strenuous. Similarly, another patient mentioned that,

"I am fortunate to have a position where they have worked hard for me to be able to work, to be able to teach, to be able to take time off. The school here, the people at levels above me have been working hard to make this effective and helpful for me."

Both of these excerpts illustrate the ways in which a large part of the patient's ability to continue working during the treatment process was due to their employer's flexibility.

***Other patients.*** While some participants avoided sharing stories with other patients for their own mental well-being, others openly embraced and sought out others in similar situations for the same reason. Many mentioned that talking to other individuals who had gone through cancer about their experiences and side-effects made them “feel less alone and comforted.” For example this participant shared:

I also had two very dear friends who had gone through treatment for breast cancer and done well. It was important to me to remain in touch with both of them for the encouragement. They were proof to me that I could beat this beast. Also, when I was feeling down they could boost my morale as they had often been through the same feelings. If side effects of the drugs were bothering me they could empathize and sometimes give me ideas of how to deal with them and what had worked for them.”

Similarly, another participant spoke about a cancer survivor and friend who she had relied on and said

“I mean I could text her at any time of day or night and I knew she would get back to me. She would say either yeah that’s normal or no that’s not normal and you need to call your doctor or something like that.”

Both of these narratives illustrate the way in which other survivors provided support for the participants either by boosting spirits or making health recommendations. In general, the participants who chose to reach out to other cancer patients and survivors were comforted knowing that they were “not alone in the battle” and that the “war was not impossible.”

***Friends and family.*** All of the participants spent time during the interview openly talking about the support they received from other friends and/or family. The support was both physical, such as helping with things around the house, cooking meals, and babysitting kids during cancer treatment, and emotional such as sitting through chemotherapy, and continual encouragement. One participant shared the amount of support she had from friends:

I have such a support group and that's been crucial for me. I don't live in the same town as my family but I have a lot of people who live in my area who come and see me, my friends here who keep gathering people to get me through it. I have another set of people in town who are taking me to the hospital and picking me up and all of these various things that have to happen that they have decided to help with. Then there are other people who have babysitters available that they have gathered. Just all of these people who are helping and that has been crucial because I haven't felt like that I've had to go through this alone in the slightest."

In this excerpt, the participant mentions that the amount of physical support also results in emotional support because she "never feels alone" despite being the only one in her position. Another participant exemplified the way in which her children physically and emotionally supported her when she mentioned,

"The kids pitched in a lot and helped a lot at home. I would sit in the chair or lay there, and I would be like okay I need you to empty the little trashcans, or dust, or vacuum and they did it. They were kind of like my own little cheerleading squad and support system to pull me through."

During the interviews, there was an overwhelming number of narratives discussing the amount of physical and emotional support each participant received from families and friends.

***Groups and activities.*** A few participants mentioned that they chose to participate in support groups or activities as a way to seek support from others. When asked about her motivation for joining a support group and participating in organized support activities, such as the Relay for Life Walk, one participant stated that she “found it comforting to be around others going through the same stuff.” This participant recollected on her Susan B. Komen experience and shared:

In fact I had just finished chemo and I ran my first Komen. I didn’t run the whole thing but I ran half of it. At that time, it was very empowering to be able to...I’m going to cry.... (cries)...like I said, I ran half of it and I had to stop because it was so hot but I was going to run that finish line, so I ran that. I started running again. It was very empowering to be with other survivors. Even though I didn’t connect with any of those people on a personal level, just being with a crowd of women and the Komen women who are survivors wear pink shirts. So you’re not looking at the white shirts. The white shirts are the supporters. The pink shirts are people like you, people that are winning. It was very empowering to be with people that were beating it. And uh..I uh.. I ran with friends’ names who were survivors but also with friends’ names who had died on my back and that was important to me. So whenever I did a Komen, those friends were there too.”

From this passage, we can understand how the participant found strength through her participation in an organized Susan B. Komen run. She mentions that, even though she was running with strangers, all of the participants in the pink shirts were immediately bonded on a deeper level, because they were all survivors or “people that are winning.” Likewise, another participant mentioned that she joined a support group called “Women Warriors” at the start of her chemotherapy treatment. The group organizes various events and activities, such as crafting projects, among women who are currently fighting cancer. She mentioned that she participated in the group because she “enjoyed watching the progress of others,” thus, once again implying that support groups were a way to motivate individuals and give them hope during the treatment process.

### **Negotiating Normals**

Due to the complex, multi-faceted relationship between work/labor and support it was difficult to parse out whether or not some participants’ passages were alluding to the ways in which they supported themselves or to the work they had to perform in order to support themselves. After hours of reflection and deliberation, I decided that the following passages were not strictly concerned with either support or work/labor but, rather, were concerned with the ways in which participants were attempting to negotiate and understand their “normal.” The process of negotiating and understanding normal took work and ultimately resulted in support. For example one participant said

My everyday life was important to me during the treatment process. I felt like I had to keep doing everything I did at home normally. You know for my sanity and my children. If I wasn’t doing things then I was just sitting around thinking

about how I'm sick, and it would really get me down. So I did everything. Yeah I mean . . . well . . . I did everything even if I didn't feel like it, I just did it. And it helped. It kept me positive and distracted, which made everything easier.

This passage clearly highlights the individuals struggle with negotiating a new normal. On one hand the participant found support and comfort by “doing everything,” because it helped her keep a positive attitude and remain “distracted.” On the other hand “doing everything” meant that she was constantly working despite how she felt that day. In other words, by not doing anything she is thrown into her new life as a cancer patient with little orientation or understanding of identity so she pushes herself to perform as much work as she can in an attempt to hang on to her previous understanding of self. She has to perform physical work in order to negotiate between her new and old normals which, in turn, supports her. Furthermore, while the work she is performing is physical, it is important to note that throughout the negotiation process she is constantly laboring mentally and emotionally in order to orient herself in her newfound normal.

Negotiating normals was organized into two categories—rejecting new normals and tools of negotiation of normals. Excerpts in rejecting new normals highlight the ways in which individuals hold onto old normals throughout the treatment process and tools of negotiation explores the ways in which individuals use tools and technologies, such as wigs, prosthetics, etc., to negotiate their new appearances.

**Rejecting New Normals.** Participants spoke about the ways in which they maintained their previously establish routine or “normal” by doing housework or going to the gym. For example, one participant said:

Uh it was very aggressive and it zoomed really fast to stage four. They were afraid of it, because it was so aggressive. I'll be honest, I was really kind of pissed and not very happy about having it again. So it's like I had the first cancer when I was 28 and they gave me five years of being scared there. And the thing about cancer is that every time you get something kind of crazy in your body you always think, ah shit it's cancer again. It takes you a long time to get past that. And I was past that. Then you know to get cervical and have a cervical scare about 6 or 7 years later was not fun either, and you know thinking okay I got a handle on this to pop up with breast cancer, all of which, none of these are related. None of these are related to anything. They just pop up! It's like I have really crappy DNA. So I was pissed off about getting it again. I wasn't devastated. I didn't really cry because kinda like the way my kids are with me, it's like "Yeah. Mom's got cancer again" (*said in a whatever voice*) so you know with me it's like "well I have cancer again but you know I take it serious and I do what I need to do because I'm proactive with it and my thing is, well okay I'm going to stomp the crap out of it because I have shit to do with my life. I'm a mom, a wife and grandma. I've got people who need me and I'm going to beat it for them. And that was it. I knew I had to do whatever they asked me to, because I knew I had to get it gone.

In this excerpt, we can see how although the participant has been diagnosed with cancer multiple times she still uses her responsibility as a form of rejecting her new normal. Rather than allowing the cancer to get her down she claims that she has to beat it because



she “has shit to do.” Among what she has to do she specifically mentions her role as a mother, grandmother and wife. She continues to perform her usual activities in each of these roles despite her illness as a way of clinging on to the comfort she found in her old normal. Similarly, another participant said, “I was determined to fight it to the best of my ability but was not very optimistic at that point. I was very worried about my husband, my daughter and mostly my 80+ year old mother. I did not know what they would do without me. I became determined that I would beat this and would not have to worry about what they would do without me, because I was going to be here with them. So I still do everything I always did, maybe even more now that I’ve lost weight and my knees don’t bother me as much.” This participant also illustrates the ways in which she uses her perceived responsibility that comes with her identity as a wife and daughter as justification for continuing her pre-cancer, normal activities. She shares that a key part of her becoming optimistic and fighting back was her responsibility to others. This responsibility and the labor/work that comes with it allow the participant to hold onto previously established concepts of normal. Rather than completely changing her life at once and preparing for what her mother may do if she does not make it, she refuses to accept that possibility. Another participant said, “My doctor told me I wasn’t allowed to work out but I said shit on that I’m going anyways because it made me feel better. It’s what I always did so I continued to do it.” Like the other excerpts, this participant’s words illustrate the ways in which she clings to her previous normal. In this case she holds onto her old normal by continuing to go to the gym despite her doctor’s wishes. The presence and comfort of the gym in this participant’s life allows her to cling to her

precancerous identity and normal. All of these excerpts highlight the overlapping, complex relationship between work/labor, support and the negotiation of normals. Participants feel supported when they can maintain some of the comfort of their old normal and that is done through the performance of both labor and work.

***Tools of negotiation.*** Some participants shared narratives concerning specific ways in which they were able to negotiate their normal through the use of technologies and tools such as wigs, prosthetics, etc. In order to highlight this section, I want to bring back a quote previously shared underneath the category work for others. The participant said “My cancer was 30 years ago but I never had the chance or the money to go through reconstruction. I had a lumpectomy on my left breast and well no one wants to walk around with a lopsided boob. It’s a confidence thing. I still wear a pad in my left bra to try to even out the size of the breast. But nothing works well.” As previously mentioned we can see the work describe in this passage, however; we can also see the tools of negotiation. In this case the participant’s daily act of stuffing her bra allows her to negotiate her post-cancerous identity. She is able to use tools, such as prosthetics and pads to stuff her bra in order to negotiate her understanding of self. Even though it is 30 years after her cancer she continues to hang onto her previous physical appearance through the use of tools showing that she has yet to outwardly embrace her new normal as a cancer survivor. Similarly another patient said

“Well at first I just used prosthetics because I thought that I never wanted to step foot into a doctor’s office again. But then you know, you have to see yourself in the mirror everyday when you change, and when you shower and, I don’t know,

that was just hard. It got to the point where I would purposely get dressed and shower in the dark so that I wouldn't have to look at the dips in my chest where my breasts used to be. I guess I just felt just felt embarrassed which is hard to because God gives you this gift that lets you live and then your feel embarrassed about what had to happen for you to enjoy that gift. So after about five months or so I decided to go ahead have the reconstruction done. It took a long time and it was a lot of surgeries but when it was all over it was nice being able to wear my old clothes again without thinking like 'oh my god is this cut to low' or 'what if my shirt moves and my scars show.' So yeah, I had reconstructive surgery but not right away."

In this excerpt the participant openly talks about the struggle she had with accepting her body after having a double mastectomy. On one hand she notes how thankful she is to be alive while on the other hand talks about the ways in which her new body emotionally affects her self esteem and identity. Rather than fully accepting her new body and new normal she uses reconstructive tools to recreate her old body. In this way the reconstruction is giving her the tools and ability to negotiate her new normal, because she is able to have surgery that makes the outward appearance of her new body resemble that of her old, precancerous body. Similarly, previously mentioned excerpts concerning the use of wigs and head scarfs highlight the same negotiation process. Tools, such as wigs, allow the participant to visibly cling to old normals despite the circumstances of their new normals. This negotiating process not only takes work/labor but also serves as a

form of support for the participant because it offers them comfort during a time in which so little in life is comfortable.

## CHAPTER SEVEN

### DISCUSSION

#### **Work/Labor**

In the preliminary study, work and labor appeared as a dominant topic, but I did not expect it to resonate so strongly in the expanded research. Throughout each interview, the majority of the participants' narratives were either directly or indirectly concerned with work and labor. If narratives truly are how we understand the world and self, then the overwhelmingly dominant role of labor in these women's narratives indicates how central labor and work are within our lives. Furthermore, during the coding process I noticed that there were significantly more narratives about work and labor related to *others* than there were about the work and labor related to *self*. However, the two were not exclusive, highlighting the multi-faceted, complex role of work in patients' lives. In other words, there were times when work or labor was initially performed for others, but could have potentially benefited the patient. This new understanding of labor as an emotional healing aid in patients' lives challenges predispositions and ideologies about what it means to be sick and how one should assume or perform a sick role. For example, in the work for self section, the participant mentions that she "didn't want to be sitting around all day thinking about being a patient all of the time so it was important for me to get back to work and get back to being as normal as possible." The participant implies that "normal" things, which include paid labor, but also unpaid work, such as cooking and cleaning, serve as not only a distraction to the illness but also as mental support. The patient feels less weighed down by the cancer when she is able to continue to do things

just as she did before. She is able to engage in the act of disidentification with her illness through work and labor, which not only safeguards her previously understood concept of self but also betters her emotional health. Often, the role of work in a patient's life is dismissed, or seen as a burden, under the assumption that patients should focus on resting and getting better, but these results suggest that the performance of paid labor and unpaid work aids the patients' emotional healing process just as rest aids the patients' physical healing process. Instead of subjecting themselves to the typical bed rest for sick patients, these participants created "new normals" and found new balances of labor, work, and rest for the well being of others as well as themselves during the course of the treatment. So in this sense, although some of the labor and support was done for other individuals, it could have potentially resulted in emotional support for the participant.

Paid work and unpaid labor's potential benefits and omnipresent roles in patients' lives post-diagnosis raises larger ideological questions and complexities that redefine and question current understandings of Marxism during times of illness. Under a capitalist society, we have been alienated from labor because our performance does not result in the production of items, artifacts, and results that we care about. Marxism's principles see labor as a burden that individuals are subjected to rather than an enjoyed activity. However, because paid labor and unpaid work have become such a large part of our normal narratives in the capitalist society, they can no longer be separated from individuals' identities and understandings of self. While this study does not justify the tendency of individuals to understand their own identity through the work that they perform, or explore why work plays such a huge role in their formation of identity, it

does suggest that work is not merely a burden, but rather a privilege in patients' lives. In these excerpts, participants repeatedly connected the idea of being mom with the unpaid work that goes with it. For example one participant said "I had to be mom and keep things normal, you know clean, and do laundry and cook every night," while another participant mentioned that she did everything she normally did both for her own sanity and for her children. These narratives repeatedly illustrate the meaningful role that the act, itself, of paid labor and unpaid work plays in individuals' lives. The labor is not a burden in this case but, rather, an opportunity for a woman to continue performing her self in ways that matter to her. This idea of the performance of paid labor and unpaid work as a privilege during the treatment process is further reiterated when we look at the ways in which various avenues of support enable the participant to continue laboring.

Interestingly, while paid labor and unpaid work were valued during the treatment process, they did not appear to have the same role once the participants were medically considered cured. For example, one participant mentioned that her cancer changed her "outlook on life" in the sense that she is less worried about her house being clean and, instead, spends more energy focusing on quality family time and relationships. Likewise, others mentioned that they believe that they care less about the unpaid work now and that their husbands share the work more equally than they did prior to their illness. The stark contrast of the role of labor during- and post-treatment should be recognized. These excerpts imply that, in the long run, the cancer experience may benefit the patient as far as labor and work is concerned, because they find themselves less subjected to disproportionate amounts of unpaid labor within the home, while at the same time raise

questions about why labor and work is so important during times of illness. During a serious illness, such as cancer, individuals are faced with moments in which their identity feels challenged and threatened. They utilize wigs, prosthetics, and other tools as an attempt to maintain bits and pieces of their identity, such as their femininity, for themselves as well as for others, but their illness is still present in their own minds. Perhaps the threat of becoming a “cancer patient” results in individuals clinging to and focusing on the parts of their lives that remain unaffected by their diagnosis. In this case, those parts of life are paid labor and unpaid work. Being diagnosed with an illness affects not only the patients’ mental understanding of themselves and their bodies, but it also affects those around them. They become consumed with thoughts of defeat and concern about cancer, and those around them begin to view them differently out of love and concern. However, the work in their lives remains stable. Whether individuals are sick or not, the tasks involved with paid labor and unpaid work remain the same, as far as expectation and outcome are concerned. In other words, sweeping the floor prior to being diagnosed and after being diagnosed takes the same amount of actual work and maintains the same results. It is the stability of paid labor and unpaid work in patients’ lives that makes it the starting point for defining new normals. This association of paid labor and unpaid work with stability results in it taking a more significant role in the patients’ lives.

### **Support**

Unlike labor, the emergence of support as a major theme did not come as a surprise. However, the manner in which support was talked about did. This study draws attention to the unexpected, complex relationship between support work/labor during



times of illness. While social support can be understood from the perspective of physical self-care or emotional, in this study support narratives were often more emotional than physical. Furthermore, the physical support that was present enabled or motivated individuals to continue performing paid labor and unpaid work or focused on helping individuals to finish some of their work tasks, such as cleaning or cooking. Occasionally, the support even resulted in more work for the patient. One participant mentioned that part of the reason she was so concerned with the house being clean and tidy was because they had more people coming over during her treatments than normal, thus increasing her awareness of the condition of the house. So, even though people were coming over to show and offer support, it indirectly predisposed the patient to more laboring, because she had higher housework standards than normal to accommodate the increase in visitors. Additionally, the emotional support present in participants' narratives helped participants' attitude while, at the same time, it encouraged them to continue to participate in labor. For example, as shown in the results, participants mentioned the students as one source of attitude support. In order to continue to receive and feel the support from the students, the participant must continue to interact with them, and the best way for that to happen is if they continue to perform paid labor.

Just as the student support highlights the ways in which support and labor/work are connected, employer support further illustrates that connection. Many of the patients mentioned the ways in which employers supported them throughout the cancer treatment process by adapting to chemotherapy or radiation schedules and, in some cases, decreasing work load by expecting them to prepare less classes. This type of employer

support is intended to enable the participant to continue performing her previously established paid labor responsibilities. However, most interesting about these narratives is the understanding of the employer adaptation as a form of “support” by the participants. Economically, it is logical for the employer to accommodate the patient in a way that enables them to continue laboring, because it prevents them from having to perform the labor associated with finding, hiring, and training replacements. Furthermore, it benefits them in the public sphere to appear sympathetic and accommodating. However, from the patient’s perspective, the added expectation of performing paid labor does not seemingly benefit the patient aside from monetary gain or insurance needs. Despite these recognized and obvious monetary and health benefits, none of the patients mentioned them as a reason to continue performing paid labor but, rather, thought of their employer’s willingness to adapt as support. When we consider the newfound prominent role of labor in the participants’ lives during the treatment process, we can begin to understand why employer accommodations were thought of as support rather than burden. The role that paid labor serves in the patient’s life makes it both a privilege and a priority, thus any accommodation that allows the patient to hang on to the stability that paid labor and unpaid work offers them is understood as support rather than encumbrance. During times of illness, the paid labor and unpaid work served as sources of motivation and places of identity work, while at the same time a large amount of the support received either resulted in more unpaid work or enabled and/or encouraged the patients to continue to perform previously established paid labor and unpaid work tasks.

### **Negotiating Normals**

Some of the narratives in this study not only highlighted the ways in which new normals affected participants' lives but also the process of negotiation that ensues once individuals are presented with new normals. It is emotionally difficult for an individual to be thrown into a new life with little to no orientation and could result in feelings of lack of social support. So in order to deal with their new illness participants find ways to hold onto past normals through activities and tools. Some individuals cling to previously established routines as a way of feeling normal while other participants utilize tools and technologies such as a wigs and prosthetics to not only make them feel normal and empowered but to appear to be normal to others as well. Understanding the ways in which individuals negotiate identities between old and new normals is a vital part of the care process. Rather than asking individuals to compromise and change every aspect of their lives we can use this research and future research to understand staple aspects of lives that should remain as unchanged as possible during the treatment process.

### **Relationship of Work/Labor, Support, and Negotiation of Normals**

Perhaps the most profound contribution of this research is highlighting the complex relationship between work/labor, support, and negotiation of new normals. When exploring individual's experiences it is nearly impossible to examine just one facet of the experience without compromising the individual's narrative by leaving complexities out. If we step back and look at the experience of mothers with cancer as a whole we see that the themes of work/labor, support, and negotiation of new normals are interconnected and messy. Take, for example, the narrative about the participant who went wig shopping with her friends. On the surface, the narrative is about buying a wig

with the support of friends, however, if we critically explore the narrative we see that it is much more complex than that. We have a participant who is in the process of negotiating her new normal. Rather than choosing to embrace her new outward appearance she decides to go wig shopping with friends. The wig gives her the tools to negotiate her normal because it allows her to hold onto her appearance in her past, old normal. Her decision to utilize a wig throughout the treatment process creates more work for her because she has to not only go through the process of putting on and taking off a wig everyday but also of maintaining the wig through washing, drying, styling, etc. Furthermore, it takes labor to be able to access the tools of negotiating. Wigs along with all of the upkeep create expenses for the patient. These expenses can only be covered through labor. Lastly, the wig offers the patient emotional support because it preserves her femininity and gives her a bridge to her old normal while at the same time, the friends who take her shopping and the employees who chip into pay for it offer her social support. We can also begin to imagine that some of that social support is only present because she continued to perform labor. Had she stopped going to work it is possible that the same collection of money would not have been taken up or that her coworkers may not have known that she wanted to go wig shopping.

Many of the excerpts, like this one, throughout this research could have easily been classified in other themes due to unexpected complexities. However, when taking the research as a whole we can see the prominent role work/labor has in the formation of our identity. The presence of work/labor in patients' lives is tremendous and in some ways, unavoidable. Just the mere identity negotiation process between old normals and

new normals creates an indefinable amount of emotional labor for patients, because they are constantly being faced with the unknown future while attempting to hold onto the known past. However, if we understand support from Albretch and Adelman's (1987) perspective as communication that reduces uncertainty, then we can propose that during times of illness, previously established routines of work and labor can serve as stable constants in patients lives and therefore the performance of it offers them identity support and allows them to negotiate their new normals and lives at their own pace. As the new normal becomes less daunting and more familiar, patients can slowly let go of routines from the old. Perhaps, moving forward, work and labor should not be thought of as a burden in a patient's life but rather an opportunity.

### **Limitations and Future Research**

While this research proved to be productive by offering insight into the complexities of life with a serious illness, it is not without limitations. One major limitation of this research was sample diversity. All of the participants identified as Caucasian women working in education and thus cannot accurately represent the role and understanding of paid labor and unpaid work in the lives of individuals of different races, due to the varying social complexities, positions, and oppressions. To avoid making hasty generalizations and assumptions about the role of labor, this study should be recreated to focus on a different race or ethnicity. Additionally, this sample focused specifically on public school employees. Public school employees are unique in that they serve a leadership role in the classroom, and it is not uncommon for them to have a personable relationship with their employers due to smaller department divisions and/or the size of

schools. It would be beneficial to focus on other employment types, such as corporate employees, to see if the roles of support and labor remain true in conditions in which the individual does not have a defined leadership role in the company and an individual does not have a strong employee-to-employer relationship. The relationship of labor, work, and support could be further explored multiple ways, including expanding this research to include a larger research audience through the use of surveys, or investigating this phenomena from the eyes of the children or husband. Furthermore, this study could be repeated to focus on a different illness in order to investigate whether or not the emphasis and importance of paid labor and unpaid work is a unique phenomenon in cancer or if it holds true to other serious illnesses. Although this research has limitations, it highlights the complexity of previously established capitalist understandings during times of physical illness.

## APPENDICES

## Appendix A

### Interview Script

**To begin:** *Debriefing and informed consent.*

#### **Interview Questions**

- Can you tell me a little bit about your cancer experience?
- Can you describe an average day before and an average day after you were diagnosed with cancer?
- Can you describe your experience as a mother with cancer?
- How did you manage the different roles you have to play on a daily basis?
- What sort of tools helped you in this process?

**To end the interview:** *Thank you for participating in my interview. If during the transcription process I have questions about your answers or what you meaning you meant to convey with them I would like to follow up with you. If it is okay for me to contact you for follow up questions will you please give me your name, phone number and email?*



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